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FROM PATIENT TO PERSON
PERSPECTIVES ON THE ROLE OF QUALITY DATA, PATIENT EXPERIENCES, AND PATIENT INVOLVEMENT IN THE IMPROVEMENT OF CHRONIC CARE

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From patient to person – Perspectives on the role of quality data, patient experience and patient involvement in the improvement of chronic care

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På ängen stod en björk.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Hälso- och sjukvården står inför stora utmaningar när det gäller framtida styrning, organisering och finansiering. Bland utmaningarna ses en växande andel kroniskt sjuka, ökade kostnader men också begränsade resurser. Kroniska sjukdomar ökar då människor lever allt längre, och tack vare förbättrad hälso- och sjukvård kan många idag leva med sjukdomstillstånd som förut var livshotande. Kroniska sjukdomar är ofta komplexa då de kräver vård över lång tid, varierar i svårighetsgrad, ofta involverar olika hälso- och sjukvårdsprofessioner samt kräver mer aktiv involvering av patienter. Parallellt med detta finns dessutom förväntningar om digitalisering och nya medicinska och tekniska lösningar inom hälso-och sjukvården. Dessa omständigheter ställer nya krav på hälso- och sjukvården som traditionellt anpassats för att hantera akuta och tillfälliga sjukdomstillstånd. Att skifta fokus mot en mer personcentrerad vård, där patienter och vårdgivare tillsammans arbetar för att skapa bästa möjliga vård utifrån individens förutsättningar, har föreslagits som en möjlig väg framåt. Men att uppnå en personcentrerad vård i praktiken är fortfarande en stor utmaning som kräver betydande insatser på alla nivåer inom hälso- och sjukvården.

I avhandlingen undersöks hur patienten och patienters erfarenheter på olika nivåer kan involveras i utvecklingen av hur hälso- och sjukvården ska utformas och förbättras. Avhandlingens utgångpunkt är att alla nivåer i hälso- och sjukvårdsystemet behöver belysas för att uppnå reell förändring, och att det historiska sammanhanget spelar roll för hur vi ser, och över tid har sett, på patientens roll. Syftet med avhandlingen är att öka vår förståelse för hur patienten kan vara, eller i framtiden bli, en viktig resurs i arbetet att förbättra kronisk vård på nationell, regional samt lokal- och individnivå.

Avhandlingen bygger på två fall (eng. case) inom svensk hälso- och sjukvård. Case A (Studie I och II) behandlar de nationella och regionala nivåerna och rör en nationell satsning på ökad användning av kvalitetsregister för förbättring av hälso- och sjukvården. Satsningen syftade bland annat till att öka användningen av patientrapporterade mått (s.k. PROM och PREM) för att åskådliggöra patienternas perspektiv. Utifrån intervjuer och dokument studeras hur stödfunktioner (registercentrum) och kvalitetsregister arbetade för att stödja användning av registerdata för förbättring av hälso- och sjukvården. I case B (Studie III och IV), som rör både lokal organisatorisk nivå och individnivå, studeras en reumatologisk klinik som arbetar för att involvera patienter både i den egna vården samt i klinikens förbättringsarbete. Kliniken utvecklar och använder flera digitala tjänster för samarbete mellan vårdgivare och patient. Utifrån intervjuer och dokumentanalyser redovisas vårdgivarnas arbetssätt och erfarenheter men också patienternas erfarenheter av dessa arbetssätt och de digitala tjänsterna.

Avhandlingens resultat ger vägledning för hur bättre vård kan uppnås genom patientmedverkan. På nationell nivå, i Case A, åskådliggörs exempelvis vikten av riktad datainsamling, dataanvändning för förbättring och hur patienters erfarenheter kan inkluderas i vården. Resultaten visar också att patienters involvering på denna nivå främst varit indirekt – i form av kvalitetsdata på gruppnivå – men att patientrepresentation också är viktigt. På regional

nivå, i Case A, hade stödfunktioner ett begränsat mandat och därför upplevdes svårigheter att nå ut till hälso- och sjukvårdens organisationer för att kunna stödja användningen av registerdata (inkl. PROM och PREM) för förbättring. Resultat från Case B visar bland annat att patienter var delaktiga i utvecklingen av nya arbetssätt och digitala tjänster på kliniken men också att patienters involvering kan utökas genom stärkta förutsättningar i form av tid, kunskap och inflytande. På lokal- och individnivå, i Case B, beskrivs patienters involvering i den egna vården och hur detta kräver delvis nya ansvarsfördelningar och roller för både patienter och vårdgivare, utmaningar med att hantera förväntningar och uppfattningar kring vem som gör vad och på vilket sätt, och att hänsyn tas till den variation som finns bland patienterna.

Genom att använda en systemsyn för att studera patienten som en resurs i förbättring av kronisk vård så skapas en bättre förståelse för komplexa och interagerande system och för den övergripande utvecklingen.

ABSTRACT

Introduction. Healthcare systems in many countries face numerous challenges including the increase in the number of chronic health conditions, the expectations that significant advances in healthcare and technology imposes, and the ever-tightening financial constraints. Chronic health problems, which often fluctuate in severity and duration, are complex. They require multiple responses over long periods of time and frequently involve several healthcare professions as well as the active involvement of patients. For these reasons, healthcare systems should take a more person-centred approach rather than a traditional healthcare approach that is designed for acute and episodic illnesses. Applying a health systems view argue that efforts on several health system levels need to be considered in order to improve care based on patients' perspectives. However, how to achieve this in practice remain unclear and challenging.

This thesis, which builds on two empirical cases (A and B) in Swedish healthcare, presents four studies ranging in setting from the national level to the patient level in order to understand how improvements in chronic care have evolved and how quality data and patient involvement have been issued at different levels in the healthcare system. The studies focuses on the patients' role in developing and improving chronic care while addressing how this role can be supported. The chronological order of the studies also illustrates how the view of the patient role has changed during the last decades, and how the patients' perspective can be captured and used for better care.

Aim. The overall aim of this thesis is to contribute to our understanding of the patient as a resource in the effort to improve chronic care at three levels in the healthcare system.

Methods. Case A (Studies I and II) investigates a national initiative aimed at increasing the use of national quality registries in clinical practice. Study I considers the macro level of national support functions (quality registry centres) and Study II considers the macro-meso level of national quality registries. Case B (Studies III and IV) investigates a rheumatology clinic with the mission of innovatively developing and using digital tools in patient-provider interaction. Study III considers the micro level of organisation and staff, and study IV considers the patient perspective and connects patients' experiences to two frameworks.

In case A, Studies I and II are multiple case studies. In study I, the sample consisted of all six quality registry centres (QRCs) in which managers and selected staff were interviewed twice. Documents (project plans, annual reports and web pages) were also collected. The material was analysed using conventional content analysis. Study II consisted of a purposive sample of nine national quality registries (NQRs). Managers and staff in key positions were interviewed and documents (annual reports) were collected. Conventional and directed content analysis were used in the analysis. In case B, Study III is a single-case study residing healthcare professionals purposively selected at the rheumatology clinic. Repeated interviews and documents (patient council meeting protocols) were analysed using conventional content analysis. Study IV is an interview study with patients at the rheumatology clinic purposively selected to provide a

varied sample. The interviews were first inductively analysed and then related to two multi-level frameworks for person-centred care and patient engagement (directed).

Results. Case A (Studies I and II) found that the QRCs and NQRs, in their support functions, adopted various strategies intended to enhance the use of quality registry data to improve healthcare work practices (e.g., by the use of patient-reported outcome and experience data). In Study I, the QRCs strategies varied from developing and adapting the quality registries' basic characteristics for improvement purposes to supporting the healthcare organisations' practical use of the NQRs. A main challenge for the QRCs was their lack of a formal decision mandate in the healthcare organisations they served. In Study II, the NQRs' focused on three strategies to enhance the use of registry data: ensuring the registration of correct and complete data; ensuring updated and understandable information available to all stakeholders; and increasing the collaboration with relevant stakeholders. While the NQRs could provide these opportunities, the stakeholders (i.e., healthcare professionals, researchers, and patients) determined how the NQRs were used.

Case B (Studies III and IV), shows the attempts by the rheumatology clinic to involve patients in their own care and in improvement efforts at the unit. In Study III, the unit employed several strategies for involving patients in their own care using digital patient-facing tools. At the organizational level, patients were involved in quality improvement practices. The healthcare professionals had to take on a flexible approach towards the varying needs among patients. In Study IV, the patients used several of the digital patient-facing tools provided to access information, communicate with the clinic, and take on more self-care responsibility. But the experiences and actual use of the tools among patients varied. Related to the two frameworks, the patients were mostly involved at the level of direct care, and/or in the process of care.

Conclusions. Systems thinking and a historical perspective contributes with an understanding of complex, interacting systems, of contextual preconditions, and of the overall process development. The findings of this thesis provides some guidance for how to achieve improved care by involving patients. At *the macro level*, the findings reveal the importance to consider the kind of aggregate data captured, the use for healthcare improvement, and how patients' experiences are captured. Hybrid support structures (as in Case A) with access at several system levels and with patient representation may provide a more holistic than narrow development perspective. At *the meso level*, the findings illuminate that the support structures in Case A had limited influence on the regional and hospital actors. The findings in Case B show that patients contributed in development of work practices and digital tools at unit and higher organizational levels. Yet, the patients' role can be reinforced by care providers creating conditions for more active patients in such development processes, which requires knowledge, time and influence for patients. At *the micro level*, the findings show that patients' involvement in their own care should consider the roles and responsibilities of both healthcare professionals and patients, flexibility towards variation in the patient group, the patient's gradual progression in the self-care role, and how to manage deep-rooted expectations and ideas about who does what and how.

LIST OF SCIENTIFIC PAPERS

I. **Granström, E**., Hansson, J., Sparring, V., Brommels, M., & Nyström, M. E. (2018). Enhancing policy implementation to improve healthcare practices: The role and strategies of hybrid national-local support structures. The International journal of health planning and management, 33(4), e1262-e1278.

II. Sparring, V., **Granström, E**., Sachs, M. A., Brommels, M., & Nyström, M. E. (2018). One size fits none–a qualitative study investigating nine national quality registries' conditions for use in quality improvement, research and interaction with patients. BMC Health Services Research, 18(1), 802.

III. **Granström, E**., Wannheden, C., Brommels, M., Hvitfeldt, H., & Nyström, M. E. (2020). Digital tools as promoters for person-centered care practices in chronic care? Healthcare professionals' experiences from rheumatology care. BMC Health Services Research, 20, 1108.

IV. **Granström, E**., Wannheden, C., Brommels, M., Hvitfeldt, H., & Nyström, M. E. Patients' views on and experiences of person-centered care practices and digital tools used in rheumatic care. Manuscript.

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LIST OF ABBREVIATIONS

NQR	National Quality Registry
PCC	Person-centred care
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
QI	Quality Improvement
QRC	Quality Registry Centre
SALAR	Swedish Association of Local Authorities and Regions

1 INTRODUCTION

Healthcare systems in many countries face numerous challenges including the increase in the number of chronic health conditions, the expectations that significant advances will be achieved in healthcare and related technology, and the ever-tightening financial constraints (Nolte, Knai, & Saltman, 2014). Chronic health problems are increasing in many countries as populations age and advances in healthcare support human survival in situations that once were fatal. In 2019, more than a third of the adults in the European Union reported long-term illness or health problem (Eurostat, 2020). These and other challenges create enormous demands on healthcare systems and highlight the need for the best possible use of scarce resources.

Chronic health conditions, which often fluctuate in severity and duration, are complex. They require multiple responses over long periods of time and frequently involve several healthcare professions as well as the active involvement of patients (Holman & Lorig, 2000). For these reasons, healthcare systems should take a person-centred approach rather than a traditional healthcare approach that is designed for acute and episodic illnesses (Nolte & McKee, 2008). An international survey of patients' experiences with healthcare services in eleven countries found that patients' involvement in the care of their chronic health conditions fell below their desired levels. The survey authors concluded there is much need for improvement in patient involvement in their own care and in chronic care management (Osborn, Squires, Doty, Sarnak, & Schneider, 2016).

The Swedish healthcare system performs relatively well in country comparisons as far as outcomes and quality of healthcare (Anell, Glenngård, & Merkur, 2012). Yet problems exist in Swedish healthcare: limited access to primary care, long waiting times, health inequities based on socio-economic factors, and inadequate care coordination (Anell et al., 2012; Wallström, Taft, & Ekman, 2017). In addition to problems with care availability and continuity, patient involvement and patient satisfaction with care are less than optimal in Sweden (Wallström et al., 2017; Westling, 2016). In response to these problems, in 2015 the Swedish Government enacted the Swedish Patient Act (SFS 2014:821). The Act aims to strengthen and clarify the patient's position in healthcare activities and to promote the patient's integrity, self-determination, and care participation.

PCC has been suggested as way to improve the care of patients with chronic and long-term healthcare conditions. While PCC approaches have not been traditionally integrated with healthcare quality improvement efforts, recent healthcare policies emphasize the value of patients' experiences that can provide complementary as well as unique information about the quality of their care (Santana et al., 2018).

In recent decades, various movements have influenced some efforts to improve the quality of healthcare. Feeley and Leitch (2017), for example, describe three development curves in healthcare services. The first curve is New Public Management (NPM) – performance management characterized by targets, rewards, sanctions, and inspections. Changes in public sector accounting in the 1980s were central to the rise of NPM and its associated principles of

public accountability and organisational best practice (Hood, 1995). NPM has been described as a performance paradigm for governance with an interest in the quality of healthcare services manifested in, for instance, the use of balanced scorecards. In Sweden, the NPM-implemented initiatives include transparent comparisons of clinical indicators across regions, increased transparency in priority settings, development of evidence-based medicine, and the use of cost-effectiveness to determine the value of services (Anell et al., 2012).

The second curve is Quality Improvement (QI). Healthcare organisations, like many other organisations, have adopted quality management processes and methods that originated in the manufacturing sector (Bohmer, 2009). QI refers to processes intended to assure and control quality as well as to methods intended to maintain continuous quality improvement using several approaches (Parry, 2014; Perla, Provost, & Parry, 2013). In healthcare, QI combines the use of healthcare professional knowledge with the use of improvement knowledge, methods, and tools. The overarching aim of QI in healthcare is to increase the quality of care (Bergman, Hellström, Lifvergren, & Gustavsson, 2015; Perla et al., 2013).

The third curve is Co-Production of care that proposes that health outcomes are co-produced. As such, these outcomes are the result of the combined capacities and behaviours of healthcare professionals and patients (Batalden et al., 2015). With this approach to healthcare, new challenges arise that require the use of new collaborative methods amongst various actors including patients. The involvement of patients in care is a key component of several related concepts with different origins in the literature, partly but not solely dependent on the place and purpose in the healthcare system in question.

According to Feeley and Leitch (2017), the current healthcare improvement movement results from the combination of these three curves that over time seek to produce better healthcare outcomes.

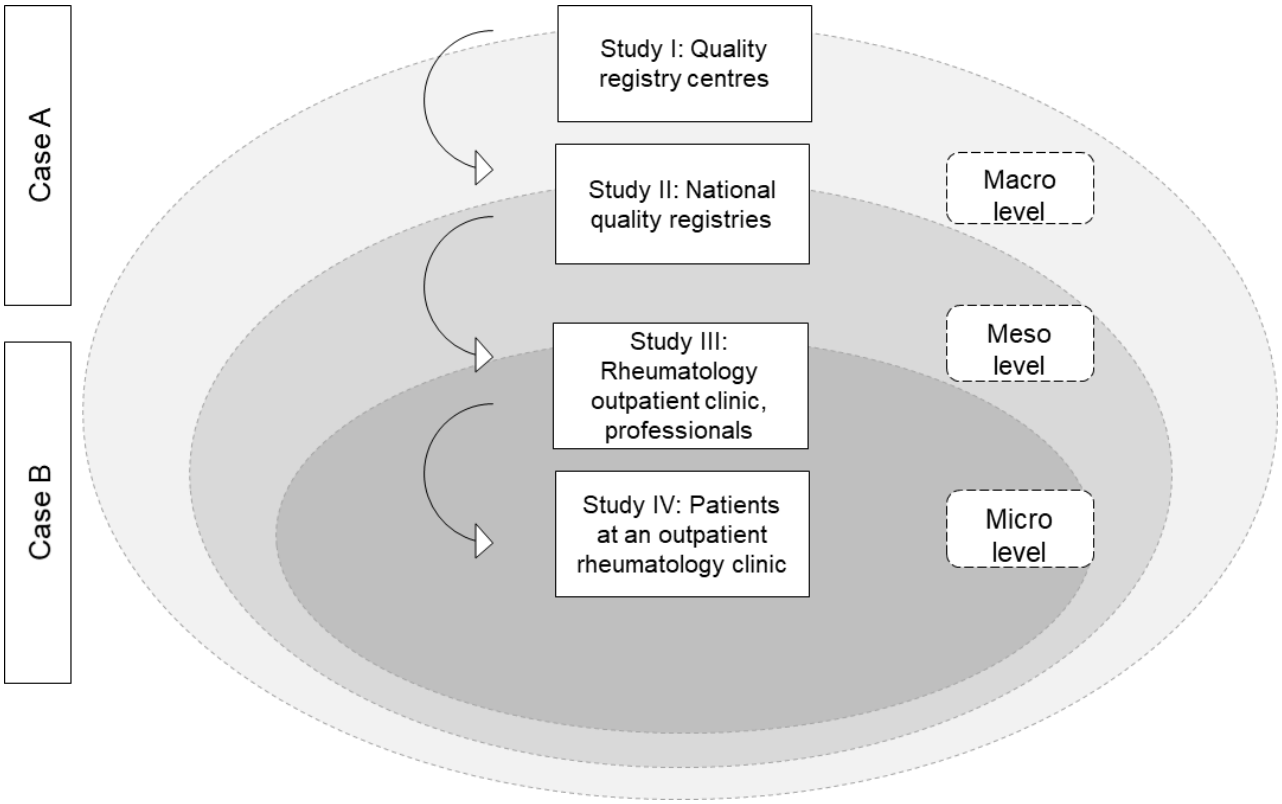
1.1 OVERVIEW OF STUDIES

The thesis investigates the role of the patient as a resource for improving and supporting healthcare practices in a Swedish context. The four studies in the thesis, while addressing different system levels and perspectives, are similar in their emphasis on the patient role – in particular, how the patient's experiences can be captured and used to improve care. Case A (Studies I and II) describes the national and regional levels of a national health initiative aimed at supporting increased use of national quality registries (NQRs) that include patient experience measures used for clinical practice improvement and patient interaction. The initiative, which broadly targeted all NQRs, indirectly targeted all healthcare and social care practices with one or more NQR connected to their practices. Case B (Studies III and IV) describes the organisation and patient levels of chronic chare, studying a rheumatology clinic where the aim was to involve patients in improving their own care and in practice development. The clinic in Case B uses the Swedish Rheumatology Registry but also other information sources.

The primary premise of this thesis is that the role of the patient should be addressed at all levels of the healthcare system. The secondary premise is that the capacities and behaviours at these

levels are either enablers of quality of care or barriers to the quality of care. Figure 1 presents a model of interacting levels which also capture the chronological order of the studies. The model begins at the macro level, descends to the meso level, and ends at the micro level: from systems level to organisational level to patient level. In practice, the arrows are two-way arrows.

Figure 1. Overview of the thesis: the four studies, the study object, and the healthcare system levels



2 RESEARCH AIMS

2.1 OVERALL AIM

The overall aim of this thesis is to contribute to our understanding of the patient as a resource in the effort to improve chronic care at three levels in the healthcare system.

2.2 SPECIFIC AIMS

Following the chronological order and the interaction amongst the levels of the healthcare system, the specific aims of the four studies in the thesis are presented next. Roman numerals refer to the four studies.

I. To investigate how support centres approached their missions of enhancing the use of national quality registries for improvement of clinical practice given their intended function and position within the healthcare system.

II. To investigate what the registry management perceived as barriers and facilitators for the use of national quality registries in quality improvement, research, and interaction with patients, and main activities undertaken to enhance their use for these purposes.

III. To investigate the overall strategies to achieve person-centred care used by the healthcare professionals at an outpatient Rheumatology clinic, the strategies' relation to digital tools used, and the perceived impact of the strategies on healthcare staff and patients.

IV. To investigate patients' experiences of involvement in their own care, in development of care practices and of the use of digital patient-facing tools at a rheumatology outpatient clinic, and relate the patients' experiences to two person-centered care frameworks.

3 LITERATURE REVIEW

This thesis builds on literature from several broad and diverse research fields. This section reviews the relevant literature on quality improvement, patient experience, and patients' own involvement at various levels of the healthcare system.

3.1 THE ROLE OF THE PATIENT AT DIFFERENT LEVELS OF THE HEALTHCARE SYSTEM

Today, patients' experiences are acknowledged as important quality of care components combined with patient safety, and clinic effectiveness (Department of Health, 2008). Some research suggests positive associations exist between patient experience, patient safety, and clinic effectiveness, and between patient experience and self-reported and clinically-measured health outcomes (Black, Varaganum, & Hutchings, 2014; Doyle, Lennox, & Bell, 2013; Manary, Boulding, Staelin, & Glickman, 2013).

In enhancing the quality of patient care, several change levels should be considered. Ferlie and Shortell (2001) describe four change levels: the individual, the group/team, the overall organisation, and the larger system. However, a multi-level approach to change does not necessarily mean that every change effort must target all levels. Rather, a multi-level approach may mean that change aimed at one level should be considered in relation to the other levels.

Three major system levels in society have been identified in social sciences research: the macro, meso, and micro levels. In a review of the person-centred care concept, these three levels are identified as the individual and interpersonal level of care (micro), the quality of care level more broadly (meso), and the health system level of care (macro) (Nolte, Merkur, & Anell, 2020). In a multi-dimensional framework for patient and family engagement, Carman et al. (2013) describe the levels of engagement in direct care, in organisational design and governance, and in policy-making.

Today, patients' opinions on the quality of care they receive are often viewed as key indicators of care quality. Their opinions are based in their direct care experiences and/or in their perceptions of healthcare systems (Nolte et al., 2020). Although it is sometimes argued that patients' opinions are too subjective to be useful (Coulter, Paparella, & McCulloch, 2020), their subjective descriptions of their experiences are not intended as substitutes for more objective clinical measurements (Manary et al., 2013; Price, Elliott, Cleary, Zaslavsky, & Hays, 2015). However, patients' opinions do add another dimension to quality of care improvement efforts as typically represented by more traditional indicators.

3.1.1 Different experience measures for different purposes

Patients' experience data can be collected in different ways. Quantitative survey data from structured, self-completion surveys are used most often to collect patients' experience data (Coulter et al., 2020; Parkin et al., 2020). Surveys, which can be analysed statistically, are popular because they can be used to compare results for entire populations or for population

sub-groups (Coulter et al., 2020). Healthcare staff members who are engaged in quality improvement efforts usually welcome more detailed and locally relevant data (Parkin et al., 2020). Such data can be collected by questionnaire surveys in which patients are contacted by letter, telephone, or e-mail, or in face-to-face interviews. To yield useful information, surveys should be well-designed, comprehension tested, psychometrically checked for validity and reliability, and implemented so as to achieve satisfactory response rates and to minimize bias (Beattie, Murphy, Atherton, & Lauder, 2015). However, the questions are usually 'closed', which means they offer a specific set of pre-defined response options. These options can create limitations when the responses are interpreted.

If response rates to surveys are low, the risk of bias may increase. For example, responses to surveys tend to be lower among men, younger adults, the very elderly, persons with poorer health, and socio-economically deprived groups (Zaslavsky, Zaborski, & Cleary, 2002). Response bias can also result from surveys with high response rates. For example, if respondents select options that they think are socially desirable, their responses may not reflect their real experiences or opinions. These issues can be handled statistically by case-mix adjustment if enough is known about the factors that influence specific responses. However, survey data users must be aware of these potential shortcomings when interpreting survey results (Raleigh, Sizmur, Tian, & Thompson, 2015).

An understanding of qualitative, unstructured feedback methods is essential when studying patients' healthcare experiences (Coulter et al., 2020). This feedback has been described as 'soft' intelligence or informal feedback (Martin, McKee, & Dixon-Woods, 2015). These feedback methods may include the use of in-depth face-to-face interviews, focus groups, patients' stories, web-based free-text comments, suggestion boxes, observations, or mystery shopping (Ziebland, Coulter, Calabrese, & Locock, 2013). They may even include "walking on to the ward" conversations with patients and staff members (Martin et al., 2015). All these methods tend to produce a deeper understanding of patients' healthcare experiences although they are generally not suitable for use as performance indicators (Nolte et al., 2020). Nevertheless, in general, staff members at healthcare clinics find patients' qualitative comments valuable and contextually insightful. This kind of data is however recognized as difficult to obtain and use owing to the time and expertise required for collection and investigation. Healthcare staff members often do not feel confident in interpreting or acting on the data or even in accepting that the data can inform improvement efforts (Gleeson et al., 2016).

Routine statistical healthcare data, however, can be used to evaluate certain elements of patients' experience such as lengths of waiting times and of hospital stays. Patients' complaints can also be used more systematically by looking for patterns and trends instead of handling each complaint as an isolated event. Inversely, patients' complaints, which often tend to be seen as 'inexpert, distressed or advantage-seeking,' are not used as relevant data that can improve care (Adams, Maben, & Robert, 2018).

All these methods for gathering data on patients' experiences have strengths and weaknesses; no single method is ideal for every purpose (Coulter, Fitzpatrick, & Cornwell, 2009). The fullest picture of patients' experiences is acquired by the use of multiple methods. Qualitative data, for example, from interviews can be used to expand the scope of structured surveys. Similarly, survey results may be used to identify issues requiring deeper investigation using qualitative methods.

It is not enough, however, only to collect data on patients' experiences – the data should be used to make improvements (Coulter, Locock, Ziebland, & Calabrese, 2014). Insufficient research is available on how organisations in their different ways use quantitative and qualitative patient experience data for making improvements (Parkin et al., 2020).

3.1.2 Degrees of involvement

Various opinions are held on how patients' involvement contributes to healthcare improvement efforts. Arnstein (1969) recommended a ladder of citizen participation that describes degrees of citizen involvement in health policy (and other policies). Her model describes the redistribution of power in several stages: from public non-participation, via tokenism, to citizen power.

Carman et al. (2013) place patient and family engagement in healthcare on a continuum – from receiving information (consulting) via becoming involved (involving) to being an active partner in the care process (partnership and shared leadership).

Bate and Robert (2006) describe the following three ways to improve healthcare. First, healthcare professionals may rely on their own experience and knowledge as they work with QI, excluding patients in the process. Second, healthcare professionals may listen to patients (e.g., via surveys and complaints) but still select the questions and the improvement goals. Third, patients may collaborate with healthcare professionals in all stages of the QI efforts.

Tritter and McCallum (2006) conclude that patient involvement cannot be measured in degrees because of its dynamic nature. These researchers think differences in knowledge and experience amongst healthcare professionals and patients should also be considered.

3.1.3 Definitions

In this thesis, the word patient is used for simplicity even if, depending on the situation, the word can refer to actual patients, their families, or other related parties (Carman et al., 2013). It is acknowledged that the word person implies a much wider and more complex concept than the word patient. As such, the concept of person incorporates the patient in a healthcare role (Kristensson Uggla, 2020). Further, chronic disease is defined as a diagnosis categorized in the biomedical system as a disease of long duration with no definite cure. Chronic illness is defined as the lived experience of long-term health disturbance when people live and cope with the disturbance. Chronic disease and chronic illness, which are highly interdependent, occur across human life spans and are largely influenced by socio-economic factors (Martin, 2007). With

respect to quality measures and digitalisation, data are defined as facts or observations about one or several patients (e.g., lab test results). Information refers to data that have been aggregated or summarized for consumers' use (e.g., information about quality and cost of care). Tools in a digital context are interactive interpretations of data or information that provide a deeper level of ongoing engagement (patient-facing health applications) (Singh, Meyer, & Westfall, 2019). Overall, IT/information systems are centrally concerned with the human act of creating meaning (Checkland, 2000).

3.1.4 Macro level – the healthcare system

Change strategies may require macro-level changes in the larger system – for example, financial incentives intended to improve quality or outcomes of care (Ferlie & Shortell, 2001). At this level, national bodies, such as evidence-based practice centres and funding and legal entities, are influential. Examples of such change strategies include the promotion of change programmes and the advocacy of change in practice settings (Holmes, Scarrow, & Schellenberg, 2012).

At the policy-making level, patient engagement may include developing, implementing, and evaluating national, state, and local healthcare policies and programmes. Patients' engagement in healthcare policies and programmes, often described as citizen or public engagement, helps ensure that the healthcare system at large is oriented around and responsive to the patients' perspectives (Carman et al., 2013). At this level, patients' engagement may include individual patients or representatives from patients' associations. Patients can collaborate with community leaders and policymakers as they solve problems, shape healthcare policies, and set resource priorities (Carman et al., 2013). Further, patient and public involvement in research can support research that is useful for relevant populations. Patients and the general public can bring about change in their roles as members in patient advisory groups, providers of feedback on various patient-facing resources, and contributors to setting research priorities (Jackson et al., 2020).

It is rare, however, for patients to have a significant degree of power and influence at the macro level (Carman et al., 2013). Further, there is insufficient research on the impact of patient and public engagement in healthcare decision-making (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). Patients' involvement can be a problematic issue depending on the underlying assumptions about such activity. On the one hand, according to the performance-based or instrumental argument, patients' involvement is justified by improved care outcomes. On the other hand, patients' involvement can be said to have a value in its own right (encouragement of self-expression and support of democratic values) irrespective of whether such involvement leads to improved outcomes or not (Morgan, 2001).

The involvement of patients or citizens in decisions at the macro (system) level requires more extensive prerequisites for system redesign. It also means that more challenges to the assumptions behind current structures arise (Nolte et al., 2020). Lord and Gale (2014) point to the mismatch between the needs of healthcare organisations (i.e., objective processes) and the needs of patients (i.e., subjective processes), as well as to the difficulties in changing routines

and organisational and professional structures. In addition, generally healthcare and political systems emphasize clinical outcomes rather than patients' experiences (Lord & Gale, 2014).

Recent progress has been made in understanding how people view the quality of healthcare services owing to the increase in the collection of patient-reported outcome measures (PROMs) and in patient-reported experience measures (PREMs). Nevertheless, the insufficiency of patient input in the development of PROMs is a problem if the goal is to capture patients' experiences as outcomes (Coulter et al., 2020). In addition, and more importantly, there is limited use of patients' opinions on the quality of healthcare services in the redesign of healthcare services (Nolte et al., 2020). Possible uses of PROMs at the macro level are system-wide performance assessments that monitor variation in health outcomes in population sub-groups and provider organisations, and to evaluate whether healthcare services deliver value for money spent (Devlin & Appleby, 2010).

In Sweden, NQRs are considered a cornerstone in the collection of nationwide PROM and PREM data. Several instruments that collect quality of life measures and patient experience may contribute to the identification of risk and protective factors, long-term outcomes, and increases in understanding quality of life aspects (Nilbert et al., 2020). Almost 90% of the NQRs include at least one PROM (Nilsson, Orwelius, & Kristenson, 2016). In a report by the NQR office it is estimated that 82% of the NQRs collect PROM and/or PREM measures (Swedish Association of Local Authorities and Regions, 2020).

Forty-one of the 105 Swedish NQRs rely on the most commonly-used instrument to collect data for measuring health-related quality of life: the EQ-5D (Ernstsson, Janssen, & Heintz, 2020). A recent study on cancer treatment revealed that only four of 30 diagnosis-specific cancer registries used PROM or PREM measures (Nilbert et al., 2020). This low rate of PROM and PREM use may partly be attributable to the varying aims of the registries (Ernstsson et al., 2020). The data collected using the EQ-5D at the NQRs were reported as quality indicators and as quality assessments and/or economic evaluations of interventions. The data were intended for quality improvement efforts, for benchmarking, and for individual patient consultations (Ernstsson et al., 2020).

Patient involvement has been a component in the structure of 82% of the NQRs' steering groups for several years (Swedish Association of Local Authorities and Regions, 2020). The development of solutions for open and easy access to real-time quality data can positively contribute to the public debate as well as underscore the need for presentation formats designed for laymen. To facilitate the interpretation of data, the varying needs of all stakeholders and end-users should be addressed. Training in data interpretation is needed for all parties (Nilbert et al., 2020).

3.1.5 Meso level – organisation

The meso (organisation) level is an important level of change as it encompass decision-making systems and operating systems that can influence the overall climate and culture for change by emphasizing teamwork, learning, and customer focus (Ferlie & Shortell, 2001). Larger

organisations consist of interdependent groups or teams, often called clinical microsystems. Patients and healthcare professionals meet in these microsystems, which are the smallest functional units of the organisational and larger healthcare system (Bergerum, Thor, Josefsson, & Wolmesjö, 2019). The microsystem – the group or team – as the focus of clinical improvement work is potentially a powerful lever for change (Ferlie & Shortell, 2001). In this literature overview, the organisational and microsystem levels are consolidated within the same level that concerns patients' involvement in the development of healthcare services. Nevertheless, microsystems/groups/teams are also closely related to the micro level.

An extensive amount of literature on change in healthcare – at the individual and organisational levels – is available. This literature often is associated with the literature that deals with improvement science and QI (Marshall & Mountford, 2013) and other theoretical fields. Those fields include learning organisations (Senge, 1990) and organisational development (French, Bell, & Zawacki, 2005) as well as improvement methods such as Total Quality Management (TQM), Continuous quality improvement, Six Sigma, and Lean. Building organisational capacity is, however, very complex work (Ferlie & Shortell, 2001).

At the organisational and governance level, patients' involvement in their own care integrates their values, experiences, and perspectives with the design and governance of healthcare organisations such as hospitals, clinics, and nursing homes. Patients partner with organisation managers and healthcare professionals as they plan, deliver, and evaluate care. Patients can also contribute by participating in the design of healthcare facilities, in hospitals' patient and family advisory councils, and in the design and execution of QI and development projects (Carman et al., 2013). At the organisational level, PROMs can be used in audits of clinics when the aim is to better understand patients' needs, to assess how well those needs are met by the organisation, and to assist with QI processes (e.g., planning innovations, monitoring progress, and incentivizing staff members (Devlin & Appleby, 2010).

When patients are involved in QI, they draw upon their knowledge, skills, and experiences that are not often used in the traditional patient-healthcare professional interaction (Armstrong, Herbert, Aveling, Dixon-Woods, & Martin, 2013). The concept of co-design, which originates in the design field (Bate & Robert, 2006), adds a usability (experience) aspect to the functionality and safety focuses characteristic of improvement efforts. Co-production of care is another concept (Batalden et al., 2015) that relates to a service view of healthcare in which patients and healthcare professionals co-produce value in service delivery and design at the individual and group levels. Patients may have various motives for their decision to involve themselves in QI (Engström & Elg, 2015). These motives include restitution following poor treatment/care, a desire for contact with staff members and other patients, a commitment to volunteerism/citizenship, a desire to make a contribution, and the satisfaction from committing to a task. However, some patients may have little interest in such QI participation. Therefore, healthcare service providers should be aware of patients' differing motives and needs to participate in QI (Engström & Elg, 2015).

There is little evidence concerning which QI programmes and techniques are useful in making care more person-centred in different contexts and settings. One criticism of these programmes and techniques is that they rarely take seriously the need to involve patients throughout the process. Another criticism is that there are too few of them to be sufficiently evidence-based (Parkin et al., 2020). Despite the recent attention paid to patients' involvement in QI, there is still no universally agreed-upon definition of the various patient involvement concepts or of the elements that these involvement concepts should fulfil (Bergerum et al., 2019). However, Bergerum et al. (2019), in a literature review, found that QI efforts that actively involve patients and that tailor these efforts to their context (to achieve the desired outcomes) support the behavioural changes that followed. Yet there is insufficient evidence in the literature on QI and improvement science to conclude that one approach to patients' involvement in QI is better than the other approaches. A thoughtful approach that is sensitive to context, engages clinical staff members, and provides strong leadership may be more important than the use of a particular programme or technique (Parkin et al., 2020).

Patients' involvement in the Co-production of care remains a serious challenge to efforts to improve the quality of healthcare (Batalden, 2018). Another major challenge relates to the difficulty in achieving sustainability in innovative projects, improvement programmes, and interventions (Braithwaite et al., 2020). Mannion and Davies (2018) propose a more nuanced account of healthcare organisational culture and the relationship between culture and performance. Lillo-Crespo, Sierras-Davó, Taylor, Ritters, and Karapostoli (2019) address the movement towards a consensus on understanding and implementation of improvement science in healthcare that includes education and training efforts. They note that this movement is still in its early stages in many countries.

3.1.6 Micro level – individual and interpersonal level of care

In Ferlie and Shortell's framework (2001), the micro level includes behavioural change efforts at the individual and interpersonal level of care such as education or leadership development amongst healthcare professionals. With less emphasis on patients' needs, the micro level increasingly provides opportunities for patients' involvement in healthcare activities. Several theoretical and empirical examples of such involvement have been observed at this level of care (Nolte et al., 2020).

Patients' involvement in their own health – treatment conditions and decisions – is a way to improve their care (Institute of Medicine, 2001; Longtin et al., 2010). Such involvement has been associated with positive outcomes for patients with chronic conditions (Bourbeau et al., 2003; Lorig et al., 1999; Shively et al., 2013). The literature describes different kinds of partnerships between patients and healthcare professionals. For example, several conceptual frameworks for patient-centred care and person-centred care exist (Constand, MacDermid, Dal Bello-Haas, & Law, 2014; Lawrence & Kinn, 2012; McCormack & McCance, 2006; Santana et al., 2018). Patient-centred care involves joint plans for treatment and care, shared knowledge with the patient, and practitioner-patient collaboration based on a partnership (Stewart, 2001). Over time, the concept of person-centred care (PCC) has been used more and more (American

Geriatrics Society Expert Panel on Person-Centered Care et al., 2016) because the concept broadens and extends patient-centred care by considering the whole life of the person beyond the clinical disease or illness (Håkansson et al., 2019). Thus, PCC emphasizes the importance of knowing persons and their context in order to engage them as active partners in their own care (Ekman et al., 2011). Nevertheless, several similarities are found between patient-centred care and PCC; both concepts include elements of empathy, respect, engagement, relationship, communication, shared-decision making, a holistic focus, an individual focus, and coordinated care (Håkansson et al., 2019).

The two care concepts differ primarily in their goals. Patient-centred care aims to achieve a functional life for the patient while PCC aims to achieve a meaningful life for the person (Håkansson et al., 2019). Differences in chronic care have also been described in terms of the continuity of interactions between individuals and their healthcare providers, and in how patients' preferences, needs, and values may evolve over time and influence that care (Morton & Sellars, 2019). Regardless of the differences between patient-centred- and person-centred care, they coexist in clinical practice. One view is that healthcare service design and delivery, with an organisational focus, should acknowledge both concepts. This thesis draws on these two concepts, acknowledges the debate on them, and uses them in a broad context.

Other concepts emphasize the collaboration between patients and healthcare professionals at the micro level: for example, Patient participation (Cahill, 1998), Co-production of care (Batalden et al., 2015), Patient engagement (Carman et al., 2013), and Co-care (von Thiele Schwarz, 2016). Although these concepts have different meanings, definitions, and purposes (Dent & Pahor, 2015), they share key components and are often used interchangeably. This situation may confuse healthcare actors who, in different ways, seek to understand and use the concepts (Lord & Gale, 2014).

In direct care, patient involvement integrates the patient's values, experiences, and perspectives related to disease/illness prevention, diagnosis, and treatment. This involvement includes management of the patient's health and the choice of healthcare coverage and providers. The patient's role ranges from the receiver of information to the active partner who sets goals, makes decisions, and proactively manages personal health matters (Carman et al., 2013). Involvement activities concerning one's own care may include co-creation of value in self-care and involvement in treatment options and decisions (Gustavsson, 2016).

At the micro level, PROMs can be used for the following activities: 1) screening and diagnosis (i.e., diagnoses that include co-morbidities and the impact on quality of life; 2) health needs assessment and monitoring (i.e., communication improvements, identification of the need for self-management support, and patient monitoring; 3) choice of providers (i.e., selection of 'the best' provider for each patient; and 4) choice of treatments and self-management support (i.e., provision of information to patients that facilitates shared decision-making and personalized care planning (Devlin & Appleby, 2010).

Patients' engagement in care at the micro level may occur without direct interaction with healthcare professionals. An increasing trend in healthcare services is that patients engage with a range of health-related resources, communities, and groups as they initiate or sustain personal healthcare practices. This activity includes seeking health information, participating in communities and self-management support groups, and consulting ratings of provider quality (Carman et al., 2013). The concept of e-patient (in Swedish the equivalent term is spetspatient) refers to patients, often with long-term conditions, who know a lot about their disease/illness, who are a self-resource for their health, and who sometimes know a good deal about healthcare generally (Ferguson & Frydman, 2004).

While a majority of people in Europe now use the Internet to search for health-related information, until few years ago only about one-fifth of this population had used digital health and care services that are provided online (e.g., requesting prescriptions or participating in online consultations (TNS Opinion & Social, 2017). The digital divide among people as far as their use of computers and the Internet is a challenge for healthcare services delivery. (Latulippe, Hamel, & Giroux, 2017) point to three aspects of this divide: principal access to the Internet (primary divide), use of the Internet (secondary divide), and comprehension of Internet health information (tertiary divide).

Increasingly however, digital technology is used in healthcare practices because it has the potential to provide improved PCC by empowering patients. Information and communication technology (ICT) can create new possibilities for patient-healthcare professional partnerships (Fors et al., 2018; Heckemann, Wolf, Ali, Sonntag, & Ekman, 2016). ICT can facilitate patients' interaction with healthcare, help them acquire more knowledge, and allow them a more active role in their own care including related decision-making processes. The use of ICT may increase patients' access to timely, sufficient, and appropriate health information that can be useful in making decisions about their care and desired level of engagement. In effect, use of ICT supports self-care and PCC (Baldwin, Singh, Sittig, & Giardina, 2017; Nolte et al., 2020; Scherger, 2009; Wildevuur & Simonse, 2015). The implementation and scaling-up of digital technologies are still in early stages; further development should include greater investment in digital infrastructure, implementation of guidelines for the safe and transparent use of digital healthcare services, increased inter-operability between systems, and investment in training healthcare professionals and the public (Nolte et al., 2020). The pandemic years (2020-2021), which have provided the impetus for speeding up this progress in Sweden, may lead to further development of digital healthcare services.

3.2 MULTIPLE SYSTEM LEVELS FOR PATIENT INVOLVEMENT

The research to date on PCC has mostly focused on the micro (individual and interpersonal) patient-professional level of care. Yet, increasingly, it is recognized that systematic implementation of such care requires consideration of patients' preferences and their involvement at organisational and system levels (Nolte et al., 2020). Some frameworks consider how to involve patients more broadly in order to achieve PCC. Santana et al. (2018) propose a framework with practical guidance for implementation of PCC. This framework,

which focuses on the foundations needed to achieve PCC, is based on a review of existing frameworks and case studies of PCC implementation. The framework is classified according to the Donabedian model of healthcare improvement into "structure", "process", and "outcome". The structural domains in the framework are the healthcare system or context in which healthcare is delivered and the pre-requisites that support the establishment of a PCC model and allow the processes (patient-healthcare provider interactions) and outcomes of PCC to occur.

Carman et al. (2013) propose another multi-dimensional framework in which patients, their families, and healthcare professionals work in an active partnership at various levels across the healthcare system in an effort to improve health and healthcare. The activities of this partnership occur in varying degrees on a continuum – from receiving information (consulting) via becoming involved (involving) to being an active partner in the care process (partnership and shared leadership). The framework describes engagement at different levels within the healthcare system – direct patient care, organisational design and governance, and policy-making. The factors that can influence the degree of engagement at the different levels link to patients (ideas about their role, their education, and their health literacy), to the organisation (culture, policies, and practices) and to society (social norms, regulations, and policy).

The differences, as well as the similarities/overlaps, amongst these approaches for involving patients at different system levels mean they are potentially complementary with respect to understanding the patient's role in chronic disease/illness care.

A system view, or systems thinking, influences this thesis that presents examples of how improvements in chronic care have evolved and how quality data and patient involvement have been addressed at different levels in the healthcare system. The two cases in the thesis (Case A and Case B) illustrate the development of chronic care improvement efforts in Sweden during approximately the last ten years. In this period, the statistical focus on gathering and using data on the quality of care, through the integration of care, has gradually changed to a more practical focus on patients' involvement and role in their own healthcare. Subsequent chapters present four empirical studies on the patient's role in developing and improving chronic care while addressing how this role can be supported.

4 MATERIALS AND METHODS

4.1 OVERVIEW OF THE FOUR STUDIES

This thesis, which builds on two empirical cases in Swedish healthcare, presents four qualitative studies that range in setting from the national level to the patient level (Case A: Studies I and II; Case B: Studies III and IV). Table 1 summarizes the four studies.

Table 1. Overview of study designs and methods.

	Case A		**Case B**	
	Study I	**Study II**	**Study III**	**Study IV**
Empirical setting	A national initiative aimed at increasing the use of national quality registries in clinical practice	A national initiative aimed at increasing the use of national quality registries in clinical practice	A rheumatology clinic with the mission of innovatively developing and using digital tools in patient-provider interaction	A rheumatology clinic with the mission of innovatively developing and using digital tools in patient-provider interaction
Perspective	Macro level – National quality registry centres' perspective	Macro-Meso-level – National quality registries' perspective	Micro level – Organisation and staff perspective	Micro level – Patient perspective
Design	Multiple-case study	Multiple-case study	Single-case study	Interview study
Sampling strategy	Purposeful, with a sample of all six support centres	Purposeful	Purposeful	Purposeful
Study participants	Managers and selected staff in key positions	Managers and selected staff in key positions	Various healthcare professionals	Patients
Data sources	Repeated semi-structured interviews and documents (project plans, annual reports, and web pages)	Semi-structured interviews and documents (annual reports)	Repeated semi-structured interviews and documents (protocols from patient council meetings)	Semi-structured interviews
Data analysis	Conventional content analysis	Conventional and directed content analysis	Conventional content analysis	Conventional and directed content analysis

4.2 STUDY CONTEXT

4.2.1 The Swedish healthcare system

Healthcare and social care services are mainly tax-funded in Sweden, and are mostly delivered by public providers in a system of care that is distributed at the national, regional, and local levels. At the national level, the Ministry of Health and Social Affairs formulates overall healthcare and social care policy. The National Board of Health and Welfare, which operates

at the national level, has a central role in developing and evaluating the implementation of evidence-based policies in healthcare and social care. At the regional level, the 21 Regions fund and deliver healthcare services (including hospital care and primary care) to their populations. The 290 Municipalities at the local level fund and deliver social care services for the elderly and for people with disabilities. The regional and local authorities are nationally represented by the Swedish Association of Local Authorities and Regions (SALAR) (Anell et al., 2012). In this decentralized system, however, the national government makes laws, issues regulations, and establishes soft governance measures such as national guidelines and initiatives that guide the healthcare sector (Swedish Association for Local Authorities and Regions, 2015).

4.2.2 Case A: National initiative for improved use of national quality registries

Studies I and II were conducted as part of a longitudinal research project with the purpose to study and learn from the implementation of a national initiative to improve the use of national quality registries, and during the process provide qualified support and feedback to the national office at SALAR aiding the efforts to meet the goals of the initiative. The aim of the project was to contribute with knowledge on key actors' strategies for supporting learning, improvement and change for those involved within the healthcare system. Data consisting of interviews and documents were collected during the course of the project, some of which was used in Studies I and II. The research team at Karolinska Institutet in Stockholm had a coordinating role and arranged meetings with the project teams at two other Swedish universities (in the cities of Uppsala and Jönköping) that had shorter and more defined projects as part of the national initiative. The team also coordinated with the Swedish Agency for Health and Care Services Analysis that evaluated the initiative.

Since the 1970s, quality registries that measure indicators of care quality have been developed and used by healthcare professionals (Jacobson Ekman, Lindahl, & Nordin, 2015). The registries, which gather and structure data nationwide on patients' diseases/diagnoses, treatments/interventions, and outcomes from care providers, use both process and results variables. Each registry has a registry management team consisting of a team of qualified healthcare professionals, healthcare researchers, and patient representatives.

The Swedish Government has supported the registries financially since the 1990s. Today, in addition to support from the national government, the registries are financed by the 21 healthcare regions (Jacobson Ekman et al., 2015). In order to meet eligibility requirements for financial support as a national quality registry (NQR), the registries participate in an annual monitoring process. An Executive Committee approves the award of financial support for the registries.

The national initiative, *Development and financing of the national quality registries* during the years 2012-2016, was an agreement between the MHSA and SALAR. The initiative, which was introduced in 2012, was government-supported for the five-year period. The initiative was expected to achieve the following: better quality of data, improved analyses and feedback for

use as support for register-based improvement activities, greater access to and utilization of quality registries in research and innovation, increased transparency and data access for patients, and improved and more equitable care. The initiative was allocated SEK 1.5 billion in funding, established a process of review (and revision) of funds allocation, and created a system for certification levels at the quality registries. The initiative also established a support structure in which three support functions were linked to the registries – the national office at SALAR, the Registry Service at the National Board of Health and Welfare, and six regional quality registry centres (QRCs). Three QRCs were assigned support functions prior to the national initiative (the competence centres). The QRCs were expected to enhance the use of the registries for improving clinical practice, for conducting research, and for creating transparency and interaction with patients and citizens. Funding for the operations of the QRCs was provided directly by the national government (via the national office at SALAR) and indirectly by the NQRs that pay for their services. The QRCs also received regional funding in various amounts. During the five years of the initiative, it was decided that every NQR must belong to a QRC. Registries joined a QRC based either on their geographic location or on their treatment speciality. For example, the psychiatric registries are clustered at one QRC.

Case A describes efforts at the national level to provide support for making improvements in the quality of healthcare practices and in participation by patients in healthcare at the national and regional levels. This support was provided indirectly in PROM and PREM development and by participation in registry management teams. One fundamental and underlying assumption in Case A, which is based in part in the quality improvement movement, is that enablers and barriers are associated with top-down change initiatives.

4.2.3 Case B: The rheumatology clinic with an innovative mission

Studies III and IV were conducted in collaboration with a rheumatology clinic (RC) that was established as an academic specialist centre in 2016. Case B was part of a larger research programme entitled *Co-care for persons with chronic illness – development, implementation and evaluation of models for partnership in care*. In this context, the RC studies were empirical case studies of a unit that was implementing existing digital tools and work practices as well as developing new digital tools and work practices. Studies III and IV, which aimed to investigate the organisational perspectives of the Co-care programme, drew broadly on theories on patient – and person-centred care (PCC) and implementation science.

The research programme had an established collaboration with the RC. The RC manager had previously been the registry holder for the rheumatology quality registry that was a pioneer in the use of digital solutions that allow patients to report outcome measurements in the registry. When the Co-care programme began, the RC was a suitable case for research because it was in the implementation phase in which digital tools are used in an organisational arrangement rather than as separate digital tools under study.

The establishment of academic specialist centres that are located outside the emergency hospitals, as is the case with the RC, is part of the Stockholm Region's healthcare plan for the

future intended to improve access to specialized care and to link research, development, and education closer to clinical practice.

The RC's mission – in addition to providing specialist care – is to develop new services and digital tools in collaboration with patients. The RC operates as an academic unit in which care is closely integrated with research, development, education, and innovation. The RC's goals are to give patients greater access to specialist rheumatology care and to broaden research to involve routine healthcare also. During the research for Studies III and IV, the RC was engaged in a pilot collaboration between the Purchasing Office of Stockholm Region (the public regional healthcare commissioner 'HSF') and the Healthcare Services in Stockholm Region (SLSO) that existed from March 2016 until December 2019. In 2017, when the RC moved to a different location, it was sequentially joined other academic specialist centres in diabetes, neurology, and obesity as permanent healthcare activities.

Case B describes the patient role at the organisational and individual levels when making improvements in patient care. Case B describes the co-production activity of improving services between care providers and patients in collaboration or in partnership. Further, Case B exemplifies the enablers and barriers associated with different kinds of feedback data intended to inform and develop the organisation.

4.3 RESEARCH STRATEGIES

This thesis uses a qualitative research methodology. Qualitative research studies are appropriate for understanding the processes by which things happen that lead to outcomes. Processes, where events and actions take place, are poorly understood using surveys or experimental research (Maxwell, 2008). Qualitative research strategies are commonly described as open-ended and inductive because of the logic and process of qualitative research in which data are collected and analysed, research questions are posed, and theory is developed outside pre-defined steps (Maxwell, 2008). The original design of research steps may alter owing to new developments or other changes. Therefore, qualitative research generally requires a flexible and non-sequential approach (Grady & Wallston, 1988). While quantitative data may have greater credibility than qualitative data for some audiences, qualitative data can generate specific details that may have significant influence for other audiences (Bolster, 1983).

Strauss (1995) explains theory as a map that explains why the world is the way it is. Theory can simplify the world by clarifying or explaining some aspect or aspects of the world. The theoretical basis for this thesis (see section 1 and 3) reviews the relevant literature (including the "grey" literature) and various interactions with other researchers and the author's own experiences. With respect to the conceptual framework for this thesis, the goal was to find theories relevant to the four studies rather than attempt to "cover the theoretical field". Therefore, the literature review aimed to identify the sources of ideas on activities and programmes as well as to identify ways of framing issues/questions (Maxwell, 2008). As result, the conceptual framework for this thesis references previous literature while retaining its unique perspective.

4.4 CASE STUDY DESIGN

The use of case studies (i.e., case study design) is appropriate for research on healthcare services and systems that are characterized by increasing complexity, rapid and continual changes, and affiliations and motivations that are difficult to track and understand (Yin, 1999). Case studies are appropriate when the research questions require in-depth descriptions of social phenomena and when the research examines open systems where events, processes, and context cannot be controlled (Yin, 2009). Many of these conditions exist in the two case studies of this thesis. Studies I and II investigate how QRCs and NQRs strive to achieve the goals of the national initiative. Study III investigates how the RC strives to improve care by involving patients. Data, collected at several time points, required consideration of the contexts in which the processes took place. Study IV is an interview study that forms a part of Case B.

The concept of "case" differs amongst the four studies of this thesis. In Case A, Study I, the cases are the six quality registry centres (QRC) that support registries and their various strategies. In Case A, Study II, the cases are nine national quality registries (NQR) with their different characteristics and strategies. In Case B, Studies III and IV, the case is a rheumatology clinic (RC) that aims at an innovative collaboration with patients. These studies examine healthcare professionals' and patients' views on the care.

Yin (2009) distinguishes four basic types of case study design as single-case design, multiple-case design, holistic design (one unit of analysis) or embedded design (several units of analysis). Various combinations of the four types are possible. Study I, which is a holistic multiple-case study, compares the strategies of six QRCs. Study II is a holistic multiple-case study that compares the strategies of nine NQRs. The use of multiple cases allows for comparisons and the identification of similarities and differences amongst them. Study III is a holistic single-case study in which healthcare professionals' experiences with PCC strategies, the strategies' relationship to the use of digital tools, and the observed effects of the strategies are investigated. The assumption is that examination of a single case (with rare or unique characteristics) can also reveal useful information (Maxwell, 2008).

Triangulation in qualitative research is the use of multiple research methods and the use of data sources from a range of individuals and settings. Triangulation is assumed to reduce the risk of systematic bias due to the use of a single research method or a single research source. Triangulation can also increase confidence in research findings through assessing the convergence of information from different sources (Maxwell, 2008; Yin, 2009).

In comments on the generalizability of case study findings, Yin (2009) describes "analytic" generalization, which refers to the idea that the studied phenomenon may have wider application than the particular case claims. Guba and Lincoln (1989) use the term "transferability" for the same idea. Analytic generalizations from qualitative studies, for example, can identify enablers and barriers similar to other situations (Maxwell, 2008). This thesis uses the case study design supported by theory in an effort to achieve a wider understanding of the phenomena studied.

4.5 DATA COLLECTION

In qualitative research, purposive sampling is used rather than probability or convenience sampling (Patton, 1990). Often, the goal of purposive sampling is not to represent a larger population; instead, its goal is to explain a setting or a population that is a special case (Maxwell, 2008). Purposeful sampling can be used to capture typicality or homogeneity in a population or to capture atypicality or heterogeneity in a population by the variation in a group rather than by study of a group member. Maxwell (2008) emphasizes that the sample decision requires knowledge of the setting or population.

The thesis consists of two types of qualitative data: interviews and documents. The interview participants in Case A, Studies I and II, were purposively selected according to their key roles and positions in their organisations. As such, the expectation was that they could respond knowledgeably to the interviewers' questions. In Case B, Study III, the interview participants were purposively selected because of their positions as healthcare professionals at the RC. In Case B, Study IV, the interview patients were purposively selected as representative of the patient heterogeneity at the RC. The documents, which were collected in Studies I, II, and III, were used to cross-check (triangulate) with other data sources (Yin, 2009).

To support the validity of research results, data should be rich, detailed, and sufficiently varied so that the data provide a trustworthy reflection of the phenomenon being studied. In the research for this thesis, three procedures were used for this purpose. First, all interviews were audio-recorded and transcribed. Verbatim transcripts are useful for maintaining the richness and details of data when analysed (Maxwell, 2008). Second, respondent validation, which decreases the possibility of misinterpreting the participants' views, was used in Studies I, II, and III. Third, in Studies I and II, over a five-year period the research team consistently referred to the national initiative, conducted interviews with the various participants, and examined protocols in documents such as minutes of steering group meetings. Long-term involvement in research is valuable for understanding the reality of the situation (Maxwell, 2008).

4.6 CONTENT ANALYSIS

This thesis uses conventional content analysis and directed content analysis in its examination of the data collected. Hsieh and Shannon (2005) describe three approaches to content analysis: conventional, directed, and summative. The three approaches differ in how codes are developed and in how theory is used in the analysis. In conventional content analysis, codes and categories are derived from the data during the analysis. This approach provides a rich understanding of the studied phenomena. In directed content analysis, prior research or theory guides the analysis, and initial codes are created based on theory. Directed content analysis allows the researcher to test or extend existing theory. Summative content analysis involves counting and comparisons, for example, of keywords or of content, which is then interpreted. In this thesis, conventional analysis was applied in Studies I and III. Studies II and IV combined conventional and directed content analyses.

Organisational categories were created prior to the data analysis. These are categories that merely sort topics from the data with no attempt at analysis (Maxwell, 2008). After the organisational categorisation, the content and the meaning of the data were analysed.

Theoretical categories place coded data in a framework. In Study II, directed content analysis was used to identify barriers and enablers. In Study IV, theory was used to map the inductively derived categories according to the two PCC frameworks (see Carman et al., 2013; Santana et al., 2018).

In case studies, connecting strategies is a process that can be used in the attempt to understand data in context by identifying relationships amongst different elements in the text (Patton, 1990). In categorizing and connecting strategies, it is less likely that important insights will be missed (Maxwell, 2008).

4.7 STUDY DESIGN, DATA COLLECTION AND ANALYSIS IN THE SPECIFIC STUDIES

This section presents the procedures used for data collection and analysis for each of the four studies.

4.7.1 Study I

Study design. A holistic multiple-case study design (Yin, 2009) was used to investigate the roles, strategies, and enablers and barriers at the QRCs. The study's aim was to investigate how the six QRCs approached their mission of enhancing the use of NQRs for improving clinical practice given their support function and position in the healthcare system.

Data collection. Six QRCs were compared in the study. The interview participants (n=13), who were purposively selected, consisted of seven QRC managers (one QRC had two managers) and six QRC staff members. The managers were assumed to have knowledge of the QRCs' overall strategies. The managers recommended staff members who understood the QRC's work with the quality improvement efforts. Twenty-five semi-structured interviews were conducted in two interview rounds in Spring of 2014 and in Spring of 2015 – with the same individuals. The QRCs' missions were addressed in the first interview round. The research questions in this round addressed how the participants envisioned the QRC role and how they thought the intended strategies would enhance the use of NQRs in quality improvement, research, and communication with patients and citizens. The assumption was that by the second interview round the participants would have more experience and could describe how the strategies were used. The interview questions in this round addressed the QRCs' perceived role and function, their support strategies, their main activities, their results, and the actors with whom they interacted. The interviews were complemented with various documents: the QRCs' project plans, the QRCs' annual reports from 2014, and the QRCs' webpages.

Analysis. A conventional qualitative content analysis approach was used to code and categorize the data (Hsieh & Shannon, 2005). This analysis focused on the QRCs' efforts in the improvement work. Strategies were identified as activities connected to intentions or goals

(Nyström, Strehlenert, Hansson, & Hasson, 2014). The strategies were then connected to actors in order to link them to the QRCs' actions. Documents were examined in order to complement and contextualize these strategies. To differentiate the various strategies, the results were mapped in two dimensions: a national-local focus and a task- or process-oriented focus. The national-local dimension identified the actors' location. The task-process dimension (inspired by (Harvey et al., 2002), identified a continuum from doing for others to enabling others.

4.7.2 Study II

Study design. A holistic multiple-case study design based on the analyses of interviews and documents was used to investigate the NQRs' conditions and strategies in quality improvement, research, and patient interaction.

Data collection. The participants were purposively selected in order to obtain a sample of NQRs that had the following characteristics: 1) exhibited some degree of maturity (i.e., certification level 1 or 2) exemplified different registry types (i.e., intervention registries, diagnosis registries, and registries focused on prevention, palliative care, or psychiatry; (Cadilhac et al., 2010; Emilsson, Lindahl, Köster, Lambe, & Ludvigsson, 2015); and 3) represented a geographical spread by location. Nine NQRs were selected (see Table 2).

Table 2. Overview of the nine National Quality Registries in the study.

	Intervention	**Diagnosis**	**Palliative/preventive**
Acute disease/ short care episode	- Swedish National Forensic Psychiatric Registry - Swedish National Registry of Gynaecological Surgery - Swedish Hernia Registry		
Chronic disease/ life-long follow-up		- Infectious Disease Registry HIV[1] -Swedish Registry of Congenital Heart Disease - Swedish Follow-up Programme for Cerebral Palsy - National Prostate Cancer Registry of Sweden[1]	- Senior alert - Swedish Palliative Care Registry[1]

[1]Registries at certification Level 1 at time of inclusion.

Data collected consisted of 18 individual interviews with two individuals from each NQR (i.e., the registry holder and a member of the registry management team who was familiar with the quality improvement, research, and patient interaction. The researcher team developed a semi-structured interview guide that asked open-ended questions about the NQRs' approaches to the three main areas and that focused on action strategies, targets, activities, interaction with other actors, and perceived change enablers and barriers. In addition to the interviews, the NQRs' websites and annual reports were examined to triangulate the descriptions of missions, goals, and activities, the scope of the NQRs, and information about staffing and financial resources.

Analysis. The transcribed interviews were analysed iteratively using both conventional content analysis and directed content analysis (Hsieh & Shannon, 2005). The analysis identified activities that the NQRs' management teams reported enhanced the use of NQRs in quality improvement, research, and interaction with patients. The information was compiled in a matrix of the NQRs' vision, activities, actors, and support from the QRCs. To identify the healthcare change enablers and barriers for the NQRs, directed content analysis was used that was patterned after Grol and Wensing's model (2004) that uses the following main categories: Innovation, Individual professional, Patient, Social context, Organisational context, and Economic and political context. A bottom-up approach was used to identify and name sub-categories.

4.7.3 Study III

Study design. A holistic single-case study design was used to investigate the following: PCC strategies used by healthcare professionals at an outpatient RC, the strategies' relationship to digital tools, and the perceived impact of the strategies on healthcare professionals and patients.

Data collection. The participants were selected using purposive sampling amongst staff members who had knowledge of and experience with the RC work practices and the digital tools used to enhance PCC and other improvements at the clinic. In addition, the sample had to include nurses, physicians, and other healthcare professionals. In the first round of interviews (n=10), the focus was on the staff members' experiences in two areas: (1) experience with the new organisational mission and the existing and emerging work practices; and 2) experience with the digital tools and e-health services (recently introduced and/or used) that aimed to trace the relationship of the work practices and digital tools to PCC practices and healthcare improvements.

Preliminary results from the interviews were then presented to the clinic's staff members in a feedback session where comments and interpretations were welcomed. The feedback session was organized to confirm/modify these results (Maxwell, 2008). Some changes were described. Next a second round of interviews was conducted with four first-round participants who had insight into the changes (n=4). In this second round, the questions addressed staff members' experience with the following: 1) work practices related to the digital tools currently in use; and 2) work practices related to interactions with patients (PCC) and improvements in healthcare practices. The interviews were complemented with documentation that described formal patient-provider interaction at unit patient council meetings. These documents consisted of patient council meeting minutes from a two-year period. The documents were used to triangulate data sources in order to increase the credibility of the interview results (Yin, 2009) as far as the role of the patient councils and the topics discussed in the patient council meetings.

Analysis. An iterative approach was used in the analysis in which conventional content analysis (Hsieh & Shannon, 2005) was applied to derive categories from the data in three steps. In the first step, units of text describing digital tools, patient interaction, and related work practices were highlighted and condensed. In the second step, the condensed units of text were classified

into two main categories depending on whether the text addressed work practices used with individual patients or used at the clinic level. In the third step, more specific categories of digital tools, work practices, and experiences were identified and named as sub-categories.

4.7.4 Study IV

Study design. Study IV was an explorative qualitative study – based on interview data – that investigated patients' involvement in their own care, the development of care practices, and use of digital patient-facing tools at the RC.

Data collection. The participants were purposively selected in order to assemble a sample that reflected the diversity in the population that consisted of patients of various ages, genders, length of illness, and illness characteristics. The participants selected for the sample also had to have been patients at the RC for at least 2-3 years. The research team did not have access to information about illness characteristics other than that which the participants shared in the interviews. A clinic nurse (not otherwise involved in the study) identified eligible patients and approached them with written information about the study. Patients who were interested in participating in the study consented to the forwarding of their contact information to the study's interviewer. Ten interviews were conducted.

A semi-structured interview guide was developed by the research group. The interview guide was inspired by concept analysis of patient participation (Cahill, 1998), key components of patient participation (Phillips, Street, & Haesler, 2016) and an anthology about strategies for person-centred health systems (Nolte et al., 2020). The interview questions addressed the following topics: 1) contacts with, and visits to, the RC; 2) participation and involvement in the care; 3) patient communication, information, and documentation; and 4) participation in care development at the clinic level. The questions were open-ended, which allowed the participants to reflect on and develop the topics. A definition of PCC was not provided to the participants in the interviews.

Data analysis. The content analysis took both an inductive and a deductive approach (Hsieh & Shannon, 2005). First, the inductive analysis examined the patients' participation in their own care, their interactions with healthcare staff, their involvement in the development and tools/services/channels for information and communication, and the integration of care and self-care experienced. Second, in the deductive analysis, the results were compared with the framework by Santana et al. (2018) that deals with practice PCC and with the framework by Carman et al. (2013) that deals with patient and family engagement in healthcare.

4.8 ETHICAL CONDSIDERATIONS

The Regional Ethics Committee in Stockholm, Sweden (Ref. no. 2014/778-31/5 and Ref. no. 2015/2216-31/5) gave ethical approval for this research.

The participants in Studies I, II, III, and IV after receiving written information about the research, gave their informed consent (either written or audio-recorded). Participation in these

studies was voluntary. Participants were also informed that all data would be confidentially handled and that participant responses would not be attributed in reports or presentations to identifiable individuals. The interview transcripts were coded in advance of the analysis, and only the researchers involved had access to these data.

Participants could withdraw from the studies at any time. Following withdrawal from a study, a participant's data would be erased from the research data base. Participants had access to the researchers' contact information and could continue to ask questions about the study by telephone or email.

In Study I, the six QRCs are identified as A, B, C, etc. In Study II, the NQRs are identified by random numbers. In Study III, the healthcare professionals are identified by number and function. In Study IV, the participants are identified by number. Quotations are coded using these identifiers.

The transcripts have been shared only with the researchers involved in the analysis. Interview files are stored on a safe server in accordance with Karolinska Institutet standards. However, as a limited number of people from quite specific contexts were interviewed for Studies I, II, and III, the participants in these studies might be identified by someone knowledgeable about the cases. Nevertheless, the information shared by the participants relates only to their professional function and does not contain any personal or sensitive information. The benefits from the studies' results should be of value to the participants, the national NQR organisation and society at large. Thus, these benefits are expected to exceed the risk of accidental disclosure.

In Study IV, patients were interviewed about issues closely related to their own disease and well-being. Therefore, the risk of possible harm from accidental disclosure was greater than that with the healthcare professionals in the other studies. However, data collected related to the patients' experiences of care – not to their health outcomes reported in medical records or in the quality registry. Regardless, there is always the risk that a study participant may form a dependent relationship with the interviewer and/or the care provider organisation. Therefore, the research team emphasized that patient participation was voluntary and that patient confidentiality was assured. These research parameters were explained in layman's language to the participants who were invited to ask questions about the research. The independency of the thesis author with respect to the RC was also emphasized. Further, as Kvale and Brinkmann (2014) concludes, participation in interviews that lead to participants' negative reflections and/or questions about their chronic diseases can be injurious to their well-being. To minimize that risk, although it cannot be completely avoided, the interviewer, where possible, maintained the interviews on an impersonal level in Study IV.

Qualitative research generally produces more contextual information about the participants than in quantitative research (Flick, 2006). In Studies I and II, the participants were given the opportunity to read a draft of the results and to comment on the interpretations, misunderstandings, and possible personal harm these results might cause them as individuals

or as healthcare professionals. Only minor changes in words and terms were made. In Study III, early results of the study were presented to all clinic staff members. They were invited to comment on these results and to propose corrections or alterations.

5 RESULTS

This section summarizes the results of the four empirical studies in the context of the overall and specific aims of the thesis. In Case A, Studies I and II examine strategies used to improve the use of quality data from the NQRs in clinical practice and for interaction with patients. In Case B, Studies III and IV examine strategies used in person-centred care (PCC) practices and the digital patient-facing tools used in such care at the organisational and individual patient levels.

5.1 CASE A (STUDIES I AND II)

Data on patient care processes and outcomes are needed to improve all areas of healthcare, including chronic care. The use of the NQRs to collect such data within various healthcare specialities by some (but not all) healthcare professions has resulted in a fragmented, partly structured situation at the overall system level. The national five-year healthcare initiative aimed to build a stronger, more integrated support structure for quality data that could be used at the national, regional, and organisational levels. The initiative clarified the role and function of the national quality registry centres and the national quality registries. During the initial stages of the national initiative, it was apparent that patients' views (in terms of PROMs and PREMs) were not well-addressed in the approximately 105 NQRs. Therefore, an area to develop during the initiative was on possible ways the NQRs' data can be represented and more transparently presented. The controlling guidance in the research is that the initiative itself emphasized data transparency, improved data access, and quality and equity in care improvements.

5.1.1 Study I

Study I takes a macro level perspective on the use of patients' data and the involvement of patients in chronic diseases/illnesses. The focus of the study is the role of the QRCs in their work to facilitate the use of NQR data in local practice improvement projects. The study's results indicate the potential exists for linking the hybrid, national-local support structure (that executes national policies) to locally-adapted support structures. In the initial years of the national initiative, to a large extent the focus was on developing the basic characteristics (e.g., indicators, coverage, and data presentations) of the NQRs in order to prepare them for use in quality improvement and development in healthcare practices. Fewer efforts were taken to enhance the actual use of the NQRs despite the increased attention from the national office (SALAR).

As a support structure, the QRCs had to connect to the NQRs but also to healthcare practices. The strategies adopted by the QRCs varied from developing and adapting the NQRs' basic characteristics for improvement purposes to supporting the healthcare organisations' practical use of the NQRs. The QRCs' approaches varied (and changed) – from the general use of task-oriented support strategies (i.e., practical and task-driven) to more frequent use of process-oriented support strategies; and from taking national responsibilities to responding to local

initiatives. While the QRCs engaged in initiatives inspired by the Breakthrough Series approach, their own approaches varied depending on their unique capabilities for supporting improvements at the local levels. Some QRCs followed pre-existing change concepts or collaborated with local development organisations. Their choice of strategies also depended on their maturity. A main challenge for the QRCs was their lack of a formal decision mandate in the healthcare organisations they served.

The NQRs capture patients' data that can be used to improve care. They also measure patients' reported outcomes and experiences. All these data were increasingly integrated by the NQRs. The participants in this study (key actors at the QRCs) were asked about their role in the patient- and citizen-professional interaction. [Although Study I presents an analysis of these interview responses, they received less attention in the published paper at the request of the journal owing to its standard format.] The interviews addressed three main topics related to the patients' role during the national initiative (2012-2016): communication with patients, engagement of patients' representatives with the NQRs' management teams and improvement teams, and the development of disease-specific PROMs/PREMs.

The work of the QRCs varied. Their efforts were directed at the following: (1) the design of reports with patients as a target group (e.g., the communication of information in layman's terms via webpages); (2) the capture of patients' healthcare information (e.g., patient's self-registration in the registry); (3) communications with patients aimed at collecting data and presenting information; (4) development and use of disease-specific PROMS; and (5) inclusion of the existing PROMs/PREMs in the disease specialities in the registries. Some QRCs worked (or proposed) to add patients to improvement teams and/or to follow-up on patient-reported measures. The QRCs also developed two guides: one guide related to the involvement of patients in NQR work; the other guide (in collaboration with the NQRs) related to QI efforts. During the initiative, the QRCs collaborated with a centre that specialised in PROMs and PREMs that was located in one of the healthcare regions. Training in the national initiative was offered to the patients' representatives.

As a hybrid, national-local healthcare support initiative, the QRCs faced various challenges as they tried to achieve the initiative's goals. These challenges arose primarily from the partnership structure with its centralized national agency partners and its decentralized, autonomous healthcare system partners. Although the QRCs had a national mandate, they lacked a formal mandate in the healthcare organisational structure at both the regional and the national levels. Also, the QRCs' were geographically connected to specific regions (e.g., the northern QRC, in Region Västerbotten, is connected to the five northern regions). As a result of this limitation, the QRCs had to find ways to contact the managers and strategic actors responsible for the healthcare organisations. For example, the QRCs could enter into short-term contracts for resources related to a particular improvement project. During the five-year initiative, the QRCs searched for and tested ways to introduce and maintain continued cooperation with regional and local healthcare organisations.

The main conclusion from Study I is that the hybrid, national-local support functions should be positioned as part of the larger national system. This re-positioning would be useful for identifying other actors and possible collaborators, and in assessing the needs of healthcare organisations. Combining the national and local change strategies would have at least two beneficial outcomes. First, the use of the NQRs would improve. Second, the QRCs' support function in the hybrid, national-local structure would improve. The second main conclusion from Study I is that the support functions (the QRCs) must use a variety of strategies if they are to reach relevant actors and to achieve multiple missions in regional and local contexts. Therefore, the QRCs must identify find ways to clarify their roles and functions in various support activities and with various stakeholders.

5.1.2 Study II

Study II takes a dual perspective on patients' involvement in chronic care improvement efforts: the perspective of the NQRs' management teams and the perspective of practicing healthcare professionals. The former group addresses the use of NQRs on an aggregate level for research and benchmarking; the latter group addresses their role in clinical care improvement at the local level. To learn how the NQRs' management teams perceived the barriers and enablers to the conduct of quality improvement, research, and interaction with patients, nine NQRs were selected for this study. Their main activities were examined.

Study II found that the NQRs' management teams mostly focused on three strategies: 1) ensuring the registration of correct and complete data (a high degree of coverage in the registry); 2) ensuring updated and understandable information was available to all stakeholders, and 3) increasing the collaboration with relevant stakeholders. These stakeholders, consisting of healthcare managers and other professionals, researchers, and patients, varied, depending on the type of registry. Like the QRCs, the NQRs lacked formal authority over the various stakeholders.

The study's participants from the NQRs described several strategies used to improve the interaction with patients. For registries with patient associations, it was common to place one or two of their representatives on the NQRs' steering committees. If a registry had no patient association, alternative ways existed to ensure patient interaction. The participants said, as registry representatives, they were regularly asked to present current registry information at the patient associations' meetings. Moreover, the NQRs interacted with patients in the design of questionnaires, information materials, and guidelines – all of which contributed to the use of NQRs in clinical development. Further, the NQRs' data in patient consultations provided important measures that supported active patient involvement in their own care (e.g., supportive self-care). In some registries, the participants described how patient-reported data, including patient-completed questionnaires, were used to discuss treatment results and illness management with patients.

Study II found that the technical development of the registries (e.g., online reporting and the possibility of registry data access for providers, patients, and the general public) were viewed

by the participants as enablers of care improvement and of patient involvement. The participants also described how the use of online reports could make meetings with department heads and patients more productive.

The participants said the collaboration with patients and patient organisations was stimulating because it supported the transparency/understanding of information important for patients. Improved access to registry data for laymen (e.g., patients) was still necessary. However, some patients' impaired cognitive skills and lack of computer skills could pose barriers to their comprehension of the registries' data.

The participants said that recent trends and a parallel focus on, for example, value-based healthcare and co-creation of care, were drivers in the development of PROMs and PREMs and of research projects in this field. However, Study II also found that involving patients in the NQRs required more direct interaction with individual patients and with groups of patients. Although the participants said the national initiative encourages these activities, much remains to be done. For example, patients and patient representatives can contribute important perspectives on the care process, the choice of variables, and the data presentation through their active involvement in the NQRs' steering committees or focus groups. In patient consultations, when clinical measures are complemented with patient-derived measures, opportunities arise for a shared and more holistic overview of patients' health conditions. These opportunities can facilitate patient interaction and co-production of care. Success with these efforts, however, depends on whether patients are invited to participate in their own care.

Study II found that while the NQRs can provide these opportunities, the stakeholders (i.e., the healthcare professionals, the researchers, and the patients) determine how the NQRs are used to achieve the initiative's goals. If an increase in the use of the NQRs is desirable, the needs of these stakeholders must be in focus. For example, the stakeholders may want information and training related to the methodologies of registry-based research, benchmarking so that they can learn from best practices, and how to involve patients and families in PCC.

Study II also found that the national initiative promoted more intensive work with development areas previously identified by the NQRs' management teams. The recent focus on value-based healthcare and other contemporary national healthcare initiatives (aimed at quality improvement and public benchmarking) were seen as enablers of healthcare advances. Yet barriers also exist. One barrier was the need to enter duplicate registrations owing to problems with the digital systems. Another barrier was the NQR management teams' lack of authority, which meant they could not enforce participation in their quality improvement activities.

Study II revealed that the national initiative supported the NQRs' quality improvement efforts, research, and interaction with stakeholders. The initiative also supported the ongoing work of strengthening the enablers (e.g., technical development) at the same time that it worked to counteract perceived barriers to this work (e.g., the lack of authority). Whether or not this support in fact helped achieve the initiative's goal was not in focus in Study II.

The Swedish Agency for Health and Care Services Analysis (2017), which evaluated the initiative, reported that even though the NQRs had made some improvements during the five years of its existence, problems still remained at its conclusion. Healthcare staff members had difficulty in analysing and using registry information at the local level. In addition, some stakeholders, including patients, said they lacked sufficient access to quality of care information.

5.2 CASE B (STUDIES III AND IV)

The transparency goal of the national initiative stated that the NQRs should present healthcare data openly for patients and citizens. Many NQRs achieved this goal while others even exceeded it. Practice-driven change processes combined with new information technology have supported patients in the involvement in their own care as they use clinical data in new ways. These processes are especially valuable in chronic care where continuous monitoring of health and disease/illness activities is essential. In the early 2000s, biological drugs were launched as a new treatment option in rheumatology. Because this treatment was aggressive, the Swedish Medical Products Agency required licensing of these new drugs and follow-ups on side effects (Essén & Lindblad, 2013). The Swedish Rheumatology Quality Registry (SRQ) maintains the follow-up records. Therefore, as reports to the SRQ increased, several rheumatology specialists increased their use of the registry. Further, SRQ began to integrate data with the medical records system. A module for patients' own registration of patient-reported outcome measures was also implemented. These measures were fed into the SRQ for use at the aggregate level and in individual decision support at clinics. During the initiative, the development and use of digital tools and digital communication (eHealth) accelerated in healthcare generally.

SRQ, which was founded in 1995, and the registry holders were clinically active at the Karolinska University Hospital's rheumatology clinic in Stockholm. This clinic was one of the specialist clinics that moved in 2016 to premises outside the main hospital and, at the same time, received a new mission: to innovate and develop their services. The clinic is referred to in this thesis as the Rheumatology Clinic (RC).

5.2.1 Study III

Study III takes the healthcare professionals' perspective on patient involvement in chronic care improvement efforts. The study investigates the strategies healthcare professionals use to promote patient involvement at the RC (in terms of PCC), the strategies' relationship to digital patient-facing tools, and the observed impact of these strategies on healthcare professionals and patients. Specifically, Study III identifies and describes ten strategies used at the RC to operationalize PCC at two levels: five strategies at the individual patient level and five strategies at the organisational level.

At the individual patient level, the five strategies used several digital patient-facing tools at the RC: 'promoting early diagnosis and early contact with new patients'; 'sharing of health information and health plans'; 'offering digital patient-professional communication'; 'shifting

tasks and initiatives from healthcare professionals to patients'; and 'providing support for self-care'. The strategies used to achieve PCC related to interaction practices with individual patients intended to improve treatment and care of their chronic condition, and the use of digital patient-facing tools in this process. All strategies dealt with the medical aspects of monitoring the disease/illness and with personalizing the treatment and social aspects of the patient-professional interaction and communication. The strategies spanned the continuum of involvement from consultation to partnership to shared leadership.

At the organisational level, the five strategies focused on quality improvement practices at the RC in collaboration with patients' representatives. Patients' involvement, which varied from indirect to direct involvement, included the following: 'using regular follow-ups of quality indicators'; 'arranging weekly unit meetings for continuous improvement and learning'; 'operating as a test and improvement hub for digital tools'; 'collaborating with patient representatives in research and development'; and 'engaging patients in the waiting rooms in improvements'. Some patients were involved in these organisational level improvements that usually aimed to capture patients' opinions and to respond to their needs. Patients were involved directly in improvement of care in two ways: as patient representatives in the patients' councils and various meetings or in specific situations when asked to participate. Patients were indirectly involved in improvement of care by offering their opinions and describing their experiences. For example, the SRQ compiled and presented PROMs at the national, regional, and local levels. The RC used these data in comparisons with their own results over time and in comparisons with data from other clinics.

The healthcare professionals said these strategies influenced patients and healthcare staff members. They identified three main effects of the strategies: 'a shift in the patient role'; 'a shift in the healthcare professional role'; and 'a behavioural and cultural change at the unit'. The shift in the patient role was described as a change from being the passive receiver of care to being an active participant in care. The patients' use of digital patient-facing tools, which facilitated this change, allowed them to join with healthcare professionals in a team effort. However, a one-size-fits-all solution was not appropriate. Instead, the healthcare professionals had to pay careful attention to when and what to introduce and manage, depending on the individual patient. A focus on the individual patient's condition meant the healthcare professionals had to move between from the more traditional way of working and towards a new way of working. They had to treat and care for patients who were likely at different stages of independency; some patients were able to take more responsibility for their own care than others. In short, the healthcare professionals described their role as coaches for patients at times and as teammates of patients at other times.

Study III, as an empirical investigation of the strategies used to involve patients in PCC at a chronic care clinic, increases our knowledge of PCC practices by its exploration of how digital patient-facing tools and work practices interact and how they may affect healthcare professionals and patients at the patient and the organisational levels. This study recommends

further investigation into the strategies and tools used to advance patient self-care. More user-friendly digital services are needed.

The main conclusion from Study III is that the use of the various digital patient-facing tools – spanning the different dimensions of patient treatment and care – facilitated the patient-healthcare professional interaction. These tools could be used to support various aspects of PCC in different ways. Although the tools did not replace other care practices, they complemented those practices when patients used them. The second conclusion is that the introduction of the digital patient-facing tools caused a shift in tasks and roles over time for the healthcare professionals and the patients. This is an area in PCC that merits further investigation.

5.2.2 Study IV

Study IV takes the patients' perspective on their involvement in their own care, on the development of care practices, and on the use of digital patient-facing tools at the RC. The study presents patients' opinions and experiences in relationship to two PCC frameworks (Carman et al., 2013; Santana et al., 2018).

Study IV categorized the patients' narrations from the interviews – their opinions of and experiences with involvement into five groups: 'social interaction', 'patient participation', 'integration of care', 'involvement of patients on unit, organisation, and system levels', and 'self-care'. Although most of the experiences described were presented in either a positive or neutral light, a few experiences were more negatively described (e.g., non-functioning interaction or lack of participation). The patients used several of the digital patient-facing tools provided to access information, communicate with the RC, and take on more self-care responsibility.

The essence of 'social interaction' was the patient-physician relationship in which patients commented on the amount of facetime with physicians and on the clinic's atmosphere/physical environment. The patients described earlier social interactions when they received inadequate attention or insufficient time as dysfunctional or substandard. Some patients even followed their rheumatologist when the RC premises moved.

The essence of 'patient participation' was the patients' experiences with shared decision-making on medical treatment, participation in care planning, and patient-initiated contact with the RC/physicians. Such participation by the patients suggested that they could contribute meaningfully to the physicians' care recommendations. However, the lack of patient participation was a negative comment in this category.

The essence of 'integration of care' was the support provided patients in addition to their medical treatment. Such support should integrate the full range of care services for patients by addressing all their needs including their psychological and physical needs. In particular, patients with multi-morbidities said they needed more support that integrated the care provided by the various caregivers.

The essence of 'involvement of patients on unit, organisation and system levels' was patients' participation in research, their indirect contributions, and/or the lack of participation. Some patients explained they did not expect to be more involved in their own care; others said they had no opportunity to be involved in care development.

The essence of 'self-care' was the patients' acceptance of their chronic disease/illness – a process that can take many years and has implications for the medical support needed. Further, 'self-care' dealt with the personalized patient support for healthy lifestyles. All patients required support in varying degrees and kind, depending on personal characteristics, illness severity, and level of illness acceptance.

The RC's various digital patient-facing tools were designed for different areas including the following: access to health information and health plans; digital patient-professional communications; task-shifting from healthcare professionals to patients; and self-care support. Study IV study revealed a more active patient role was enabled by the use of the RC's digital patient-facing tools. The tools could be used to provide patients with more flexible access to information, to give them the opportunity to assume a larger role in their own care, and to encourage them to take the initiative in scheduling appointments (e.g., time, place, problem).

For several reasons, however, actual use of these tools by patients varied. First, the patients had different understandings of their chronic condition. Second, patients had varying access to the digital tools. Third, some patients had weak computer skills. Fourth, the digital patient-facing tools were introduced at different times, which meant that some were more accepted and used than others.

Study IV concludes that the digital patient-facing tools can complement or improve on the more familiar "traditional" medical care practices because, for many patients, the tools are fairly easy to learn and use. Their use implies that the patient role in self-care can expand as patients take more responsibility for their own care.

In Study IV, patients' involvement in self-care and their use of digital patient-facing tools were examined in the context of two PCC frameworks. These frameworks, which partly overlap in some respects, complement each other. Santana et al.'s (2018) framework, which includes details on several PCC domains at different healthcare system levels, does not offer guidance on the degree, extent, or quality of PCC. Carman et al.'s (2013) multi-dimensional framework presents levels of involvement on a continuum but offers little guidance on which PCC elements that should take place on each level. In that framework, the patients' experiences and their use of digital patient-facing tools occur mainly at the level of direct care (at the middle and higher ends of the involvement continuum). Further, some patients' experiences/digital use relates to the organisation and system levels of the framework (at the lower end of the involvement continuum – in consultation– when patients enter data into the quality registry).

In the comparison of Study IV's results with results from the framework by Santana et al. (2018), the PCC process domain dominates although categories are also noted in the PCC

structure and outcome domains. Use of the digital patient-facing tools as intended matched in these three domains. However, in Study IV, the patients gave more complex descriptions of the individual-related process effects that did not quite match the two outcome domains of more "formal" measures. Additional analysis aimed at explaining patient-reported outcomes and other outcomes may be needed.

6 DISCUSSION

This thesis increases our understanding of patients as a resource in chronic care improvement efforts with its insights on how patients are, and can be, involved at several interacting healthcare system levels.

6.1 MAIN FINDINGS

The main findings from Case A (Studies I and II) are that the QRCs and NQRs, in their support functions, adopted various strategies that were intended to enhance the use of quality registry data in efforts to improve healthcare work practices (e.g., by the use of patient-reported quality data). The QRCs had a rather complex hybrid national-local mission because, although nationally-established, they were located in the different healthcare regions. Therefore, the QRCs had to collaborate with their assigned regions in order to function at the regional/local level. Variations existed in how the QRCs collaborated with their regions and built on existing regional structures. In general, the QRCs in Study I lacked an official mandate from the NQRs and the healthcare organisations for the practice improvements they were supposed to support.

The NQRs in Study II were not homogeneous as far as the preconditions related to clinical practice improvements, patient interaction, and research. These preconditions variously influenced how the NQRs tried to achieve the goals of the national initiative. Study II identified several problem areas for the NQRs. For example, a greater focus was needed on the variety amongst stakeholders so that improvements could be made in contextually-adapted information and training, registry based research methods, and benchmarking methods. In general, healthcare professionals needed to learn from best practices and patients and their families needed to be more involved in person-centred care.

Study II also found that patients' involvement in their care was targeted by collecting PROM and PREM measures, to increase the transparency and comprehensibility (by the use of layman language) of data presentations, and to involve patients in the registry management teams. Although the study identified new ways of patient involvement in PROM development and in data capture, these projects and ideas were not widespread at the time of this thesis research (2013-2014).

The main findings from Case B (Studies III and IV) relate to the attempts by the rheumatology clinic (RC) to involve patients in their own care and in the improvement and development efforts. The RC is innovative in its mission (i.e., to develop new digital patient-facing tools) and in its structure (close proximity to patients, separate from the main hospital). The RC used several strategies aimed at achieving PCC work practices at the individual patient level and at involving patients in care improvement efforts. New work practices meant changes were required in how the healthcare professionals and the patients understood their roles and assumed their responsibilities. The changes in PCC work practices were more formal and more specific than the changes required for the roles and responsibilities.

The RC did develop new PCC work practices and did implement digital patient-facing tools. However, the two studies found that the varying patient group (with their different preconditions) differed in their adoption of these new ways of working. Patients' use of the digital tools and patients' assumption of the new self-care role (with its greater responsibility) varied. Ultimately, the patients were more involved in the care at the patient level than they were in the care at the clinic, organisation, and system levels.

6.2 SYSTEMS THINKING ON ACHIEVING IMPROVED CARE THROUGH PATIENT INVOLVEMENT

Systems thinking – an inspiration for the perspective taken in this thesis – was used in this research to increase our understanding of the patient as a resource in chronic care improvement efforts. Systems thinking in healthcare has been emphasized for advances in public health (Carey et al., 2015), as ways to strengthen healthcare systems (De Savigny & Adam, 2009), and for synergies between perspectives such as sense-making and double-loop processes (Nyström, Tolf, & Strehlenert, 2020). Santana et al. (2018) and Carman et al. (2013), who used several system levels in their frameworks for PCC and patient engagement addressed the PCC elements needed at each level to achieve PCC or greater patient involvement in chronic care improvement efforts. Both frameworks posit that extensive changes in the entire healthcare system are needed. Best et al. (2012) list the following basic rules that, if followed, may increase the likelihood of success when such large system transformations are made: blend designated leadership with distributed leadership; establish feedback loops; attend to history; engage physicians; and include patients and families. In addition a supportive policy framework aligned with a strategic vision vis à vis the patient role in the improvement of care will advance the development of PCC (Nolte et al., 2020).

In a review of the implementation of PCC, Liberati et al. (2015) identified several care enablers such as committed senior leadership and the greater involvement in care by healthcare staff members, patients, and the wider community. Nolte et al. (2020) argue that successful PCC, in a culture of change and learning, requires systematic measurement and feedback so as to continuously monitor patients' experiences.

The PCC research generally focuses on the interpersonal level (i.e., the interaction between the care provider and the individual patient). The contextual issues at other levels have rarely been addressed explicitly, particularly at the systems level. Other theories, such as patient and public involvement, have focused on patient involvement in individual care and on healthcare service development at the local and national levels (Fredriksson & Tritter, 2020). Patient involvement is also influenced by the relationships between the various actors and institutions and by the regulatory, economic, and cultural contexts of organisations and systems.

At all system levels, the various actors' roles, including their degree of involvement, should be addressed so that patients can influence their care. The overarching challenge, however, is finding a way to achieve this in practice. The four studies in Case A and Case B offer some guidance.

6.3 THE CHALLENGES OF PATIENT INVOLVEMENT AND THE USE OF PATIENT REPORTED DATA FOR IMPROVEMENT AT DIFFERENT LEVELS

Table 3. Overview of cases, system levels and how patients were involved.

	Macro system level (national level)	**Meso system level** (regional level)	**Micro system level** (organisational clinic level, patient-care provider level)
Case A – National initiative to support the use of NQRs	National structure and resources for gathering, analysing and supporting the use of patient reported data, PROM, PREM	QRCs' and NQRs' geographic spread and organisational placement under responsibility of regions to enhance the use of patient-reported data, PROM, PREM in all regions	Healthcare professionals (active in their profession) as registry holders (NQRs) and as researchers into improvements at their clinics
		Patient representatives involved in NQRs	Patient representatives involved in NQRs and in support initiatives in improvement teams
Case B – Rheumatology clinic with an innovative mission	Development of the rheumatology NQR; patient's own registration (PER) module was strengthened by the national initiative	Regional decision to provide resources intended to fulfil a new mission aimed at innovation and development	Work practices involving healthcare professionals and patients in clinic level improvements
	National support (e.g., the national web-based healthcare service platform, 1177.se, and technical solutions, such as a secure log-in for patients	Digital patient-facing tools developed at the RC, over time with increasing input from patients	Work practices and digital tools involving patients' in their own care

As noted above, two patient involvement conceptual frameworks in particular attempt to bridge the patients' experiences/opinions and the different system levels: Carman et al. (2013) and Santana et al. (2018). The Carman et al. framework, which describes various degrees of patient and family engagement on a continuum, provides little guidance on which PCC elements should apply at which level. The Santana et al. framework describes several PCC domains – Structure, Process, and Outcome – and what they may or should contain, but does not offer guidance on the required degree of PCC.

As presented in Case A (Studies I and II), patient involvement was achieved mainly through indirect means: the development and use of PROMs and PREMs and the participation of patient representatives in the NQR management teams. As such, these activities fall into the Structure and Process domains of Santana et al.'s framework, which suggests various structural conditions must be in place and processes must be implemented at the interpersonal level if PCC is to be achieved. This framework also describes the Outcome domains that should be identified and measured as follow-ups to PCC. In summary, while Santana et al.'s framework expands the perspective of patient involvement at several system levels, further expansion is

needed to include the structures, processes, and outcomes for patients at the organisational and healthcare system levels.

As presented in Case B (Studies III and IV), the RC's work practices involved patients in their own care in various degrees. Carman et al.'s framework, with its continuum of engagement, is useful for interpreting the studies' findings with respect to patients' use of the digital patient-facing tools where some patients used these tools more than others. As in that framework, the patients in Study IV thought they were involved in their own care and, in some cases, considered themselves active partners in their direct care. At the organisational and healthcare system levels, patients were mostly consulted (i.e., surveyed about their experiences) although the RC also involved patients in improvement projects and in patient councils.

In summary, patients' involvement, in particular at the meso and macro levels, requires further consideration. Carman et al. conclude that some patients may seek greater involvement in their own care. However, these authors also issue warnings. For example, patient involvement at the higher end of the continuum may not be ideal for all patients in all situations. Further, it cannot be assumed that all patients have the ability and/or the interest necessary to take on the self-care role and responsibilities.

Concerning the cases and the three system levels, the micro level is not directly applicable in Case A (Studies I and II) except in the clearly-defined improvement projects and in the presentation of relevant data on a regular basis. The presence at organisational levels is however stronger where clinically active healthcare professionals are engaged in the NQRs.

The macro level does not clearly apply to Case B (Studies III and IV) because these studies are not strongly anchored at the healthcare system level. The development and improvement in work practices and digital patient-facing tools occur at the meso and micro levels where healthcare professionals and patients meet at the organisation and in face-face meetings (e.g., at the RC). While the NQRs (from the macro level) are used, their use is limited and does not fully reflect the clinics' outcomes.

6.3.1 Macro level

The macro level consist of regions in collaboration, the Swedish Association of Local Authorities and Regions (SALAR), and their collaboration with the government. Actors at the macro level must facilitate collaboration between various actors and with authorities so that it becomes easier to develop relevant and useful support and ways of following up quality in healthcare.

The challenges at macro level in order to provide a support structure for healthcare improvement and patient involvement are several.

1. QRCs and NQRs as hybrid organisations
2. Patient representation and education
3. Patient-reported data

A challenge with the QRCs and the NQRs as hybrid organisation is the interface between national and regional/local levels, where NQRs are supposed to be used for different purposes at different levels. There is a point in having a support structure outside the formal healthcare system that can provide an overall system view, but the forms for this need consideration. The challenges at macro level also concern representation and education of patients. When patients are involved as representatives for a perspective, who do they represent? Who are willing to participate and how can they be equipped to be able to be an active partner? What is important in order to be able to contribute? Further, the macro level is far away from clinical practice – with a longer distance to the patients. If the goal is to achieve a healthcare that enables health promotion, prevention and self-care, patients may need more knowledge and understanding about their own disease as well as how the healthcare system works. Is there room for that in the way healthcare is designed today?

On a system level, the use of NQRs has limitations and have to be complemented with other data sources. First, the approximately 105 NQRs do not cover all of healthcare responsibilities and provides an incomplete picture. Second, among the areas covered in NQRs, the reporting of PROMs and PREMs remain patchy, and when they are used, a variety of instruments are used for collecting data. This makes comparisons over clinical specialities difficult, while it may be less of a problem in disease-specific comparisons. To be useful in clinical practice, instruments need to capture the disease-specific features and changes over time. To have patients (and other stakeholders) involved in the development of PROMs and PREMs will probably make the instruments more accurate. However, how patient-reported measures are used, as compared to other clinical measures in the NQRs, to inform practice improvement is even less known. Further, it is also important to consider what these surveys do not capture regarding patient experiences.

Further, it is important to emphasize that the scope of this thesis does not encompass cases on all levels. The level of the national actors such as the government, national agencies, SALAR, the political levels, are important stakeholders that have not been explicitly addressed.

There has not been any policy initiatives specifically targeting person-centred care in Sweden, but an example in line with the development is the national health reform ‘God och nära vård’ (SOU 2020:19) that was launched for achieving available, geographically close, continuous and integrated care from the patient’s perspective. This reform needs to see the movement on several system levels.

6.3.2 Meso level

The meso level is the level at which the regions exercise their authority to provide healthcare to residents. It is at this level that the regions cooperate with the municipalities. Actors at the meso level are required to support care providers in the use of (patient-reported) quality data and to engage in care development and improvement activities at the micro level. Management at the meso level must follow up on such activities by evaluating results and by engaging in dialogue with care providers on these results.

The challenges to the structure for healthcare improvement and patient involvement at the meso level primarily relate to the following topics:

1. Patient representation and education
2. Care integration (for patients with co-morbidities)
3. Patient-reported data
4. Complementary data requirement

All these challenges are more closely linked to practice. The reason is that there is more care provider-patient contact at the meso level because of regular and follow-up check-ups and because of established healthcare professional-patient relationships.

Organisational restrictions can be problematic at the meso level as far as the use of NQRs that link to clinical specialities. For example, some organisations (or clinics) may have several registries in their practices. Further, these registries do not always capture data that are valuable for the design of follow-up QI measures. Moreover, insufficient data analysis – with subsequent translation into activities – creates a problem for continuous learning follow-up. It is difficult to achieve behavioural and/or culture changes if the NQRs do not provide useful measures.

Legal restrictions that focus on aggregate-patient use (vs. individual-patient use) by the NQRs can also be problematic. Thus, care providers need complementary data sources or technical solutions that capture PCC information.

6.3.3 Micro level

The micro level is the level where patients and care providers meet. The care providers include the care teams, the support systems, and the organisation managers. At this level, value that makes a difference must be created. Actors and groups at the micro level require access to and use of the most valuable high-quality data. Efforts that focus on patients' needs and their experiences should be spread and promoted.

The challenges to the structure for healthcare improvement and patient involvement at the micro level primarily relate to the following topics:

1. Variety of patients' preconditions
2. Patients' roles and responsibilities
3. Limitations for patients / integrated care

There are, and will be, varying preconditions among patients to take on a bigger role in relation to healthcare and self-care. In order to ensure equal opportunities and access to care, special focus should be put on patients that do not use digital tools. Those who do not seek care or are active are likely those who need it the most (Latulippe et al., 2017).

In order for patients to have an influence in several parts of the care process, e.g. design, execution and evaluation, there needs to be certain pre-conditions in place. Person-centred work practices have potential to create opportunities for patients to take on a broader role. However, formal work practices are easier to change, e.g., with the introduction of digital tools,

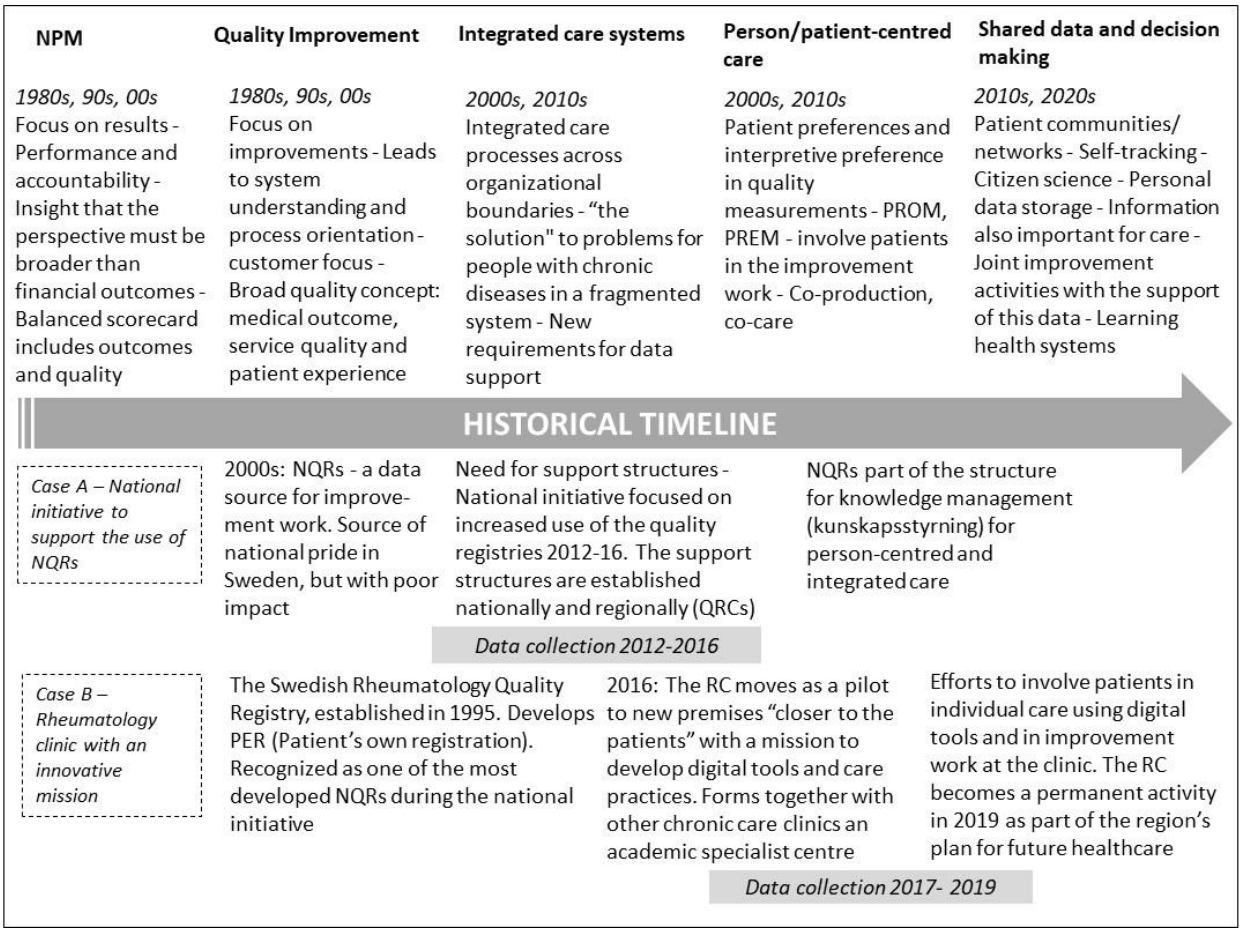
than the cultural shift needed to actually realizing and executing their inherent potential to change the roles and responsibilities of patients and healthcare professionals. This also requires training of healthcare professionals.

Today, measurements and patient involvement are moving towards a more personalized development and patients want an overall picture of their care. But there are limits in the profession, the organisation, and in the healthcare system. Integrated care for each individual patient could be a way forward, with opportunities for both horizontal integration across sectors and vertical integration across system levels. This calls for integrated data systems, perhaps with patients themselves as owners or co-owners of their own data. For example, a recent study in chronic care suggest a model for new ways of sharing patient-controlled data (Hager, Lindblad, Brommels, Salomonsson, & Wannheden, 2021).

6.3.4 A historical perspective

Over time, various societal and healthcare improvement movements have exerted different influences on the development of healthcare and chronic care. Figure 2, which illustrates these movements, or trends, over time in Sweden, positions Case A and Case B relative to such movements.

Figure 2. Historical timeline of improvement movements and case A and B



The timeline is not a complete representation of all societal trends, contextual factors, and historical events that influenced the two cases. Rather, the timeline is an attempt to place the two cases in a historical frame that helps us understand the influences that shaped the national healthcare initiative (i.e., the NQR initiative) that is at the core of the research for this thesis. Historical perspectives are useful for understanding how national healthcare systems develop.

6.4 IMPLICATIONS FOR RESEARCH AND PRACTICE

6.4.1 Research

This thesis increases our understanding of the historical development of Swedish healthcare (at the macro, meso, and micro system levels) in the specific context of how patients' can contribute to the improvement of chronic care. Two PCC frameworks (Carman et al., 2013; Santana et al., 2018) provide conceptual inspiration for this research although both frameworks are somewhat incomplete and lack the historical perspective.

Thus, the ambition in this thesis is to take both a systems thinking perspective and a historical perspective. The research revealed other areas that merit additional investigation, as described next.

Change of most kinds is evolutionary. Therefore, future research would benefit from more long-term analysis. With the identification of trends and movements over time, opportunities arise to identify and strengthen successful approaches and practices. For this purpose, case studies, which provide rich information, are especially useful for such complex approaches and practices.

More research on the use of healthcare partnerships in patient self-care is needed. PCC, which tends to focus on the healthcare profession within healthcare environments, would benefit from further development of models that incorporate several system levels and several dimensions of patient involvement. The research by Carman et al. (2013) and Santana et al. (2018) could be helpful in this development.

The promotion of patient involvement, e.g. the use of digital patient-facing tools, is clearly needed in QI research, especially amongst patients who have weak computer literacy and little Internet familiarity. Further, a single system lens (with the patient at the centre of focus) tend to be too narrow as other stakeholders also need to be considered. A study by Dawson (2018) draws this conclusion in which patients' satisfaction is linked to staff members' satisfaction. In quality improvement models, the roles of different stakeholders and how these roles change – including policy makers, managers on different levels, support functions and patients – could be further clarified.

6.4.2 Practice

This thesis, which is based in systems thinking and which takes a historical perspective, has practical implications for change that may help policy- and decision-makers gain a broader

perspective on healthcare systems. The practical implications from the four studies of this thesis are presented next.

Practice at the macro level: The QRCs and NQRs should focus more on collecting data on patients' experiences for use as quality-of-care indicators. At present, not all NQRs collect PROM and/or PREM data. Those that do, use a variety of instruments and therefore, useful comparisons between clinical specialities are rare. To be useful in clinical practice, instruments need to capture the disease-specific features and changes over time. Involvement of patients (and other stakeholders) in the development of PROMs and PREMs will probably improve the accuracy and comparability of measures provided by the instruments. Further, it is important to be aware that these instruments do not capture everything of importance related to patients' experiences.

Practice at the meso level: Greater focus is needed on the use of patient-reported evidence and on the clinical view of best quality of care. Further, for effective use of NQRs in clinical practice, contextual knowledge is essential. This is the knowledge that healthcare professionals, patients, and other care providers can provide. Therefore, discussions are needed amongst stakeholders about comparisons of data and changes over time that can improve care.

At this level, it is also worth addressing how individual patient variation is captured and used. The individual approaches to care should be weighed against standardized approaches to care. What are the advantages and disadvantages of patient-tailored care compared to the advantages and disadvantages of "one-size-fits-all" patient care? The issue is whether premises about hierarchies of evidence (i.e., scientific and technical evidence) should rank above clinicians' practical experiences and, even more so, above patients' experiences (Greenhalgh, Snow, Ryan, Rees, & Salisbury, 2015).

Practice at the micro level: More analysis is needed of the interpretations, adjustments, and other developments related to chronic care treatment and management. The closer the care is to the patient, the more important it is to collect data that complements the overall care picture. Changes in patient and provider roles imply new roles, responsibilities, and expectations, all of which require that actors have the relevant knowledge and competence. Inevitably, variations in patient involvement will occur owing to patients' attitudes/abilities for assuming a new role with new responsibilities (e.g., the use of digital patient-facing tools for self-care). The healthcare professionals' role will also develop: the professional expert role will be complemented with a partner role.

Finally, further development of a multi-level model that can facilitate the practical work of patient involvement in self-care is recommended.

6.5 METHODOLOGICAL CONSIDERATIONS

Qualitative longitudinal research in real-life settings provides opportunities and poses limitations for the researcher. The main opportunities are access to interesting/unique case settings and the gradual build-up of trust between the researcher and the study's participants.

These opportunities allow the researcher to investigate backgrounds, histories, and locations, and to establish increasing mutual confidence so that the participant responses are richer in information, more reliable, and more "open." The researcher's reliance on the acquired, in-depth knowledge supports the research interpretations and conclusions. On the other hand, research in real-life settings can create methodological limitations when the researcher tries to broaden interpretation to generalization, to balance privacy with open expression, or to compare current data with past data. Unexpected contextual changes may also alter the design and scope of the original research plan.

In Case A, an action-oriented approach in the research project led to the gradual engagement and trust was built over time with the national office at SALAR. Data that were collected over time in a data base and the research resulted in several studies – two of which (Study I and Study II) are reported on in this thesis. In Case B, the research project encompassed several studies with three clinical tracks (rheumatology, neurology, and oncology) and two perspectives (organisation and management, and informatics). Two studies (Study III and Study IV) are reported on in this thesis.

The four studies built on the relationships amongst researchers, practitioners, and patients. Neither SALAR (in Case A) nor the rheumatology clinic (RC) (in Case B) influenced the research focus, analyses, or conclusions. SALAR granted access to meetings and documents; the RC facilitated the researchers' access to the studies' participants and documents.

The four studies offer different perspectives on how patients are involved in quality-of-care efforts, and in reference to their own care. However, both Case A and Case B seek to understand care processes rather than care outcomes. Hence, this research provide limited guidance on "what works." It is recognized that other research approaches might strengthen the findings from this research. First, increasing the number of cases could provide an even more comprehensive view of how patients are, and can be, involved in their own care. Second, quantitative surveys with questions on patients' experiences could increase our knowledge of how they perceive and engage in improvement efforts. Third, the use of observations, focus groups and examining additional documents could provide richer data as well as allow more triangulation of data sources.

Specifically, in the context of the Case A studies, research focused on care improvements could explore how the participants thought the use of PROM and/or PREM actually contributed to the improvement efforts. Specifically, in the context of the Case B studies, research did to some extent, but could further focus on how healthcare professionals and patients though patient might contribute to the care improvement efforts. In both instances, such research would take a more outcome approach than the four studies of this thesis.

This thesis has been inspired by Malterud et al.'s (2016) 'information power' concept in the determination of an accurate sample size in qualitative studies. The more relevant information a sample provides, the fewer participants are needed. According to these authors, information power depends on the following: the aim of the study – narrow to broad; the sample specificity

– dense to sparse; the use of theory – applied to none; the quality of dialogue – strong to weak; and the analysis strategy – case to cross-case.

According to Maxwell (2008), two well-known threats to validity in qualitative research are researcher bias and researcher effect. Researcher bias refers to how the researcher's beliefs and/or expectations influence the study, rather than trying to eliminate variance between researchers. In Study II, a physician-researcher was selected as one of the three researchers in the study. The assumption was that this researcher, who could more easily gain the trust of the physician-participants, would obtain and document accurate (i.e., valid) responses. Researcher effect refers to the influence of the researcher on the participants interviewed. The concern in all the interviews in this research was that the questions might elicit responses assumed by the participants as socially acceptable to the researchers. Besides the longitudinal action oriented approach that is built on trust, the researchers clearly explained the purpose and scope of the project, asked no leading questions, and gave no indication they were evaluating the responses in any way in order to avoid the researcher effect. Moreover, in Studies I, II, and IV, which were telephone interviews, the remote (not face-to-face) settings meant the researchers could not unintentionally communicate approval/disapproval by body language or facial expression. Nor could the researchers jump to conclusions based, for example, on the participants' ages, appearances, or gestures.

7 CONCLUSIONS

The overall aim of this thesis is to contribute to our understanding of the patient as a resource in the effort to improve chronic care at three levels in the healthcare system (macro, meso, and micro levels). A systems view and a historical perspective contributes with a holistic understanding of complex systems to be used in combination with an understanding for processes in the subsystems at the different healthcare levels. The historical context highlights contextual enablers and barriers for different courses of events to appear and visualize the overall process development.

At the macro level, the findings reveal the importance of addressing the data captured at the aggregate level – how data are used in healthcare improvement work and how data represent patients' experiences. The findings at this level also show a need for efforts to provide guidance for how captured data translate from information into care action (including an overarching analysis model and its interpretation process). A hybrid support structure, as described in Case A, with access at several system levels may provide a more holistic understanding than a narrow perspective. Such support structures can gain from involving patient representatives, if they have the competence and knowledge needed to make useful contributions at this level. To date, however, based on the findings from the Case A studies, patients play a rather passive role at the macro level as far as chronic care improvement efforts based on NQR data. The influence they have is quite fragmented.

At the meso level, the findings reveal that the support structures described in the two Case A studies have little influence on the regional and hospital actors. However, the findings in Case B show that patients can contribute to the development of work practices and digital patient-facing tools at the unit and the higher organizational levels. When patients take a more active role, there is greater need for more patient knowledge, time, and influence. Care providers have to create the conditions that can meet this need, for example by releasing information about work methods and services that do not function as intended, and by identifying which actors to involve in the development and use of digital patient-facing tools.

At the micro level, the findings reveal that several aspects of patient self-care (which require greater patient responsibility) should be addressed. These aspects include the healthcare professional's role, the patient's role, variations in the patient group, the patient's gradual progression in the self-care role, and the management of deep-rooted expectations and ideas about who does what and how. This conception of patient self-care requires a change in roles and responsibilities, a development process for actors, and increased flexibility by healthcare professionals as they meet variation amongst patients.

8 FÖRFATTARENS TACK

Det finns många som varit betydelsefulla för mig under de här åren och som jag därför skulle vilja tacka. Först vill jag rikta ett stort tack till de verksamheter och personer som deltagit i mina studier.

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